Centre for Professional Practice

Death anxiety and burnout in end of life care: Can addressing death anxiety reduce health care workers' burnout and improve self-perceived helping relationship skills?

A thesis submitted to the University of Kent for the Degree of Doctor of Philosophy in Medicine and Health Sciences

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ABBREVIATIONS

BLI	Barrett Lennard Inventory
C	Congruence
CG	Control Group
CGM	Carol Gouveia Melo
D	Depersonalisation
E	Empathy
EE	Emotional exhaustion
EG1	Experimental Group 1: HCWs working with patients with a terminal condition in other units
EG2	Experimental Group 2: HCWs working with patients with a terminal condition within palliative care unit
EOL	End of life
FJD	Fear of being judged and losing dignity
FLS	Fear of loneliness and abandonment
FM	Fear of not having meaning in life
FP	Fear of pain
FU	Fear of the unknown
HCW	Health Care Worker
MBI	Maslach Burnout Inventory
PC	Palliative Care
PCAn	Principal Component Analysis
PCA	Person Centred Approach
PCU	Palliative Care Unit
PF	Professional Fulfilment
SD	Standard deviation
T1	“How I feel today” (immediately before training)
T1p	“my perception today (4 months after training) of how I was before training”
T2	“How I feel today” (4 months or more after training)
UA	Unconditional Acceptance

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I have many people to thank in this long journey, and so I will start in the order of appearance.

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ABSTRACT

Background: Death anxiety may interfere with health care workers' (HCW) relationship with patients and families and increase their levels of burnout. This study shows the impact of a six-day intervention for HCWs based on personal introspection on death anxiety followed by training in communication skills and emotional and spiritual support to patients.

Methods: A quasi-experimental mixed methods approach was used with a pre-test, post-test design with 4 months interval.

- Quantitative methods: questionnaires were given to evaluate levels of burnout, personal well-being, death anxiety and the quality of HCWs' relationships with patients.
- Qualitative methods: The post-intervention questionnaires contained open ended questions for content analysis, and interviews were carried out.

Results:

- Quantitative: 150 HCWs involved in caring for patients with a terminal condition (85 in palliative care units and 65 in other settings) were involved in the study. There was a control group of 26 HCWs who cared for patients with a terminal condition in settings other than palliative care units. Comparison of results before and after the intervention revealed a significant reduction in levels of burnout and death anxiety and a significant increase in personal well-being, professional fulfilment, and perception of the quality of their relationships with patients and patients' families.
- Qualitative: 94 participants answered the open ended questions and 26 participants were interviewed. The results supported the quantitative results with the exception of burnout, where HCWs seemed to suffer more from burnout than implied by the results of the quantitative data. The results also provided an understanding of the difficulties experienced by the HCWs and the impact of the intervention.

Conclusion: The original contribution of this research is to show that an intervention designed specifically to address death anxiety and helping relationship skills can reduce HCWs' levels of burnout and improve self-perceived emotional and spiritual support to patients and families.

1. INTRODUCTION

1.1 AIM AND ORIGINAL CONTRIBUTION

The main objective and contribution of this research was to evaluate an existential training intervention based on the self-development of health care workers, and helping relationship skills, and to ascertain if this would enable them to better cope with burnout and death anxiety.

The secondary objectives were to ascertain if the intervention would:

- Have a positive impact on emotional and spiritual care to patients and their families;
- Improve the quality of the relationship HCWs have with patients and their families;
- Improve the well-being and working conditions of HCWs.

This research aimed to understand the impact that this specific type of preparation would have on the well-being of HCWs, and subsequently, from the HCW's subjective point of view, on their patients. It can be considered to be complementary to training in palliative care, because it approaches an important area of palliative care: giving the HCW the emotional tools and necessary preparation to capacitate them to put into practice the philosophy of palliative care with less risk of engaging in avoidance behaviours and suffering from burnout. To our knowledge, it is the only intervention of this type in Portugal, and although there have been many similar ones in other countries, none have been found that cover the combination of issues approached under the same kind of pedagogic format that gives individualized attention to each participant.

1.2 BACKGROUND

I started my career as a psychologist on a voluntary basis giving psychological support to patients with AIDS at the Curry Cabral Hospital in Lisbon. I witnessed situations that were difficult for HCWs to deal with: A patient died, and within 15 minutes they were carted off in a black plastic bag and the bed was made for the next patient. The other patients in the infirmary would watch and often say "That's what's going to happen to me when it is my turn". Most of the patients were drug addicts who had abandoned or been abandoned by their family and were dying on their own. There was a high rate of depression and aggressive behaviour among these patients. Dealing with families could also be very stressful for HCWs: informing them of the patient's deterioration or death caused them anxiety and dealing with family conflicts and conflicts between patients was also a difficult task. Some of these patients were men who had contracted the disease through prostitutes and in another ward, wives who had contracted the disease through their husbands, sharing the same ward with the prostitutes. Physical suffering and unsightly manifestations of the sickness were always present, because at that time, HIV was not well controlled and patients died of the disease.

There was no support of any kind for the HCWs. I noticed that doctors would often do their rounds without much interaction with the patients; informing families of deaths was a task that was either avoided or done in an impersonal manner; some nurses and doctors became quite 'hard core' and other more sensitive nurses left after a while. I also noticed that nurses were overworked and even if some wanted to sit with patients to give them some emotional and spiritual support, there was no time. I performed an initial research which I finished in 2003 measuring burnout in HCWs, stress and self-esteem in patients and the quality of care provided, both from the HCWs point of view and the patients. The results showed for the HCWs a correlation between levels of burnout and the quality of their helping relationship. However, this study had no qualitative data and also did not take into consideration the HCW's personal well-being. It became clear that there was a need to develop a support system for these professionals. One year after this study, I joined the association "AMARA-Associação pela Dignidade na Vida e na Morte" that trained volunteers to give emotional and spiritual care to patients with a terminal condition and their families, and for this, they received six days training. After that, they were given the emotional support and supervision they needed to continue their work. The association then started to give this same training to HCWs with very positive feedback from them. At this time, emotional support for HCWs in Portugal was virtually non-existent. Little research was found regarding interventions designed specifically to help HCWs who cared for patients with a terminal condition to reduce their burnout and improve the quality of their helping relationship towards the patients.

Understanding the importance to focus on ways to improve the capacity of HCWs to deal with stress and death anxiety in situations as described above, I decided to start a large scale research to deepen the scientific knowledge in this area. The research was performed with the financial support of the Calouste Gulbenkian Foundation and was taken to a PhD level with the support of the Foundation of Science and Technology in Portugal, and the University of Kent in the United Kingdom (UK).

1.3 THEORETICAL DEFINITIONS

Research has shown that **health care workers (HCWs)** who care for patients with a terminal condition, both within and out of **palliative care** can suffer from **death anxiety**. This can lead to **burnout** and in turn affect the HCW's capacity to engage in an effective helping-relationship with the patient and family. (Lowry, 1997; Keidel, 2002; Bernard & Creux, 2003; Connelly, 2009). The underlying causes may be the HCWs' own fear of death, feelings of inadequacy, insufficient understanding of the needs of patients with a terminal condition, and difficulties in communicating (Lowry, 1997; Keidel, 2002). **Self-development** combined with enhancing one's helping-relationship skills may be one form of overcoming these obstacles. The following paragraphs will briefly define these terms:

In this study, the term "**Health Care Worker"** (HCW) was used to refer to all trained health professionals who cared for patients in their area of expertise. In this particular case, they were nurses, nursing aides, doctors, psychologists, social workers, physiotherapists, nutritionists, occupational therapists, hospital chaplains and unit secretaries who had direct contact with patients and families.

The term “**helping-relationship”** was used following Carl Roger’s theory of Person Centered Psychotherapy. Rogers defined the term in 1958 in his classical article “The characteristics of a helping relationship” where he states that a helping relationship is where at least one of the parties has the intent of promoting growth, development, maturity, improved functioning and improved coping with life of the other (Rogers, 1958).

The term “**self-development”** has a very wide scope of action. Self-development in this thesis was narrowed to existential issues related to increasing meaning in life. It was based on the works of authors such as Viktor Frankl (1963), Marie de Hennezel (1998), Ira Byock (1996; 2004) and Morrie Schwartz (Schwartz, 1997; Albom, 2003), and encompassed the following areas:

- An understanding of the past and how this has shaped the person today;
- The quality of relationships with loved ones;
- Living life with meaning: present and future;
- Understanding how the way one lives life can prepare for the way one dies;
- Getting to know one’s personal resources to face obstacles, adversities and the unknown;
- Coping with aging and physical degradation.

Self development in this research was achieved through sharing within a group, with the presence of a **facilitator.** The role of the facilitator followed the Person Centred Approach which is to create an atmosphere within the group that allows the members to express their feelings freely. This is achieved through empathy, unconditional acceptance and congruence: the facilitator tries to understand the members of the group’s feelings without passing judgment and creates an atmosphere whereby the group members can do the same for each other. The facilitator needs to be congruent within the group in terms of:

- Transparency: what the facilitator is experiencing is in agreement with what she expresses to the group;
- Authenticity: there is a match between how the facilitator thinks she is experiencing what she really is experiencing: the facilitator needs to be conscious and aware of her thoughts and feelings so that these do not interfere with the relationship and so that an atmosphere of trust can be established;
- Appropriateness: what is disclosed by the facilitator needs to be for the support of the therapeutic work within the group.

If the facilitator successfully develops these three attitudes, the experience of being fully understood and accepted will create the desire among the group members to adopt the same attitudes towards each other and subsequently, towards their patients. (Mearns & Thorne, 1988).

“Death anxiety” has been defined as “a negative emotional reaction provoked by the anticipation of a state in which the self does not exist” (Tomer & Eliason, 1996, p. 345). It has also been suggested that the fear expressed by patients with a terminal condition may be the same type of fear that people experience “in everyday life rather than in acute situations where there are immediate threats to life...[It] has multiple components including: anticipating [oneself] dead, fear of the process of dying and fear about the death of significant others" (Payne, 1998, p. 701). Other such existential fears may include: fear of pain and suffering, fear of being alone and of not having close and fulfilled relationships, fear of living with uncertainty, fear of the unknown, fear of not living a meaningful life, fear of physical degradation, fear of losing one's dignity and being judged by others, and fear of what comes after death (Hennezel & Leloup, 1997). In this research, the term "death anxiety" was used to refer to these existential fears. Lack of awareness of the existence of these existential fears in their own lives may lead HCWs to experience feelings of anxiety when caring for patients with a terminal condition, which can in turn interfere with the HCW-patient relationship (Lowry, 1997; Meier, et al., 2001).

The term "**end of life care"** has been used throughout the thesis to refer to care given to patients with a terminal condition, both in and out of palliative care units. The definition is not entirely agreed upon and it has been suggested that end of life care is "care that combines the broad set of health and community services that care for the population at the end of their life" (Palliative Care Australia, 2008) or as: "care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support" (The National Council for Palliative Care, 2011)" This definition also suggests that this care is for: "people whose death is imminent (expected within a few hours or days) and those with:

(a) Advanced, progressive, incurable conditions

(b) General frailty and co-existing conditions that mean they are expected to die within 12 months

(c) Existing conditions if they are at risk of dying from a sudden acute crisis in their condition

(d) Life-threatening acute conditions caused by sudden catastrophic events".

For some people the appropriate start for end of life care might be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease" (The National Council for Palliative Care, 2011).

Thus the start of the end of life phase is often unclear and may be seen as "a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less. Although the term "End of life care" may be imprecise, it does imply time-defined care. It may be seen as a more quantitative rather than qualitative descriptor and thus excludes the purpose of care. This thesis will use the term to cover people with advanced progressive and incurable disease as defined by the National Council for Palliative Care. However, in Portugal, end of life does not necessarily cover all the points mentioned in their working definition of end of life care.

In contrast to the uncertainty of the definition for end of life care, palliative care is not time-confined but goal-oriented" (HSE Clinical Strategy and Programmes Directorate, May 2013). The term "**palliative care"** was used mainly in this thesis to refer to the sample of HCWs who worked in palliative care units as opposed to the other sample of HCWs who cared for patients with a terminal condition in other units. The World Health Organisation definition states:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

It goes on to state that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (World Health Organization, 2002).

It is clear therefore, that palliative care can be applied at any stage of the life threatening illness, and not only in the final phase where death is imminent.

The term "**other units**" will be used for HCWs who care for patients with a terminal condition in units without specific palliative care provision. The term "**terminal condition**" has been defined as "a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The condition is inclusive of both malignant and non-malignant illness and aging" (Palliative Care Australia, 2008).

Burnout has been defined as "a syndrome of emotional exhaustion, depersonalization and reduced personal accomplishment that can occur among individuals who work with other people in some capacity" (Maslach, et al., 1997, p. 192). HCWs' burnout and death anxiety can affect patients, institutions, and HCWs themselves in many ways. It can lead to poor quality of care, increased absenteeism and job turnover, and personal dysfunction (physical exhaustion, insomnia, increased use of alcohol and drugs, and marital and family problems) (Maslach, et al., 1986).

There is little research on the effectiveness of learning to cope with existential fears, or **"death anxiety"** and how this anxiety can affect patient care and burnout. Previous research has focused on ways of addressing the root causes of burnout and on improving patient care through a mix of educational and emotional support strategies (Pronost & Tap, 1996; Delvaux, et al., 2004; Fillion, et al., 2005; Wasner, et al., 2005). HCWs have been shown to benefit from various types of education, including instruction on how to maintain awareness of the emotional aspects of dealing with suffering. As such, it has been suggested that to enable HCWs to help patients on an emotional and spiritual level, it is not sufficient to simply educate them about the patients, but HCWs also need to learn how to get in touch with their deeper selves and to be aware of their own spiritual beliefs (Wasner, et al., 2005); “Clinicians need to pay attention to their own spiritual histories and to be conscious of how this affects the care they give their patients” (Sulmasy, 2002, p. 31), so that HCWs must recognize their own fear of death, suffering and helplessness before they can allow themselves tos be close to patients with a terminal condition (Hennezel & Leloup, 1997) .

1.4 RESEARCH QUESTIONS AND HYPOTHESES

The central question of this research was “Can an intervention addressing a combination of personal well-being related to existential issues and practical helping relationship skills reduce health care workers’ burnout and increase their perception of their capacity to engage into an effective helping relationship”?

The main hypothesis to this central question was that: ***as a result of a reduction in death-related fears, an increase in existential well-being and an increase in the perception of their own competence in their helping relationship skills, HCWs would experience a significant reduction in their levels of burnout and a significant increase in their perception of their capacity to engage in an effective helping relationship with the patient and family.***

This central question was decomposed into the following questions and hypotheses:

1 - The first aim was to establish whether the intervention was successful in increasing personal well-being and HCWs perception of their competence in helping relationship skills:

Q1: Will the intervention improve the HCWs personal well-being and perception of their competence in helping relationship skills?

H1: The intervention is an effective instrument to improve levels of HCWs’ personal well-being and perception of their competencies in helping relationship skills.

This could be shown by comparing results of the following factors over time:

- Increased self-confidence, dignity and meaning when faced with adversity and illness;
- Decrease in “no time for family and meaningful activities”;
- Increase in closer personal relationships and well-being;
- Decreased fear of dependence, physical degradation and loss of control;
- Increased empathy and congruence;
- Increased unconditional acceptance and positive regard;
- Decreased avoidance mechanisms;
- Decreased distance and impatience towards patient.

2 - Once this had been established, the aim was to understand whether there was a relationship between personal well-being together with perception of competency in helping relationship skills and levels of burnout:

Q2: Will an intervention that addresses personal well-being and helping relationship skills reduce burnout?

H2: As a result of an improvement in personal well-being and perception of their own competencies of helping relationship skills, there would be an expected reduction in levels of burnout.

H2a) Comparing results of the following factors over time:

- Increased professional fulfilment;
- Decreased emotional exhaustion;
- Decreased depersonalization.

H2b) Performing correlation analyses:

- There is a positive correlation between:
  - The negative factors of the helping relationship (avoidance mechanisms and distance and impatience toward patients) and the negative factors of burnout (emotional exhaustion and depersonalization);
  - The positive factors of the helping relationship (empathy and congruence and unconditional acceptance and positive regard) and the positive factor of burnout (professional fulfilment);
  - The negative factors of personal well-being (fear of dependence and physical degradation and no time for family and meaningful activities) and the negative factors of burnout (emotional exhaustion and depersonalization);
  - The positive factors of personal well-being (close personal relationships and meaning in life and self-confidence in face of illness and adversity) and the positive factor of burnout (professional fulfilment).

3 - In order to establish whether there was an increase in the perception of HCWs' capacity to engage in an effective helping relationship as a result of their increased well-being, there was an aim to understand whether there was a relationship between personal well-being and the helping relationship:

Q3: Will an increase in personal well-being, increase the capacity to engage in an effective helping relationship?

H3: As a result of an improvement in personal well-being, there would be an expected improvement in the HCWs' perception of the quality of their helping relationship with the patient.

This would be undertaken by looking at correlations of:

- A positive correlation between:
  - The positive factors of personal well-being (close personal relationships and meaning in life and self-confidence in face of illness and adversity) and the positive factors of the helping relationship (empathy and congruence and unconditional acceptance and positive regard) ;
  - The negative factors of personal well-being (fear of dependence and physical degradation and no time for family and meaningful activities) and the negative

factors of the helping relationship (avoidance mechanisms and distance and impatience toward patients);

Fig 1 shows this in a different way:

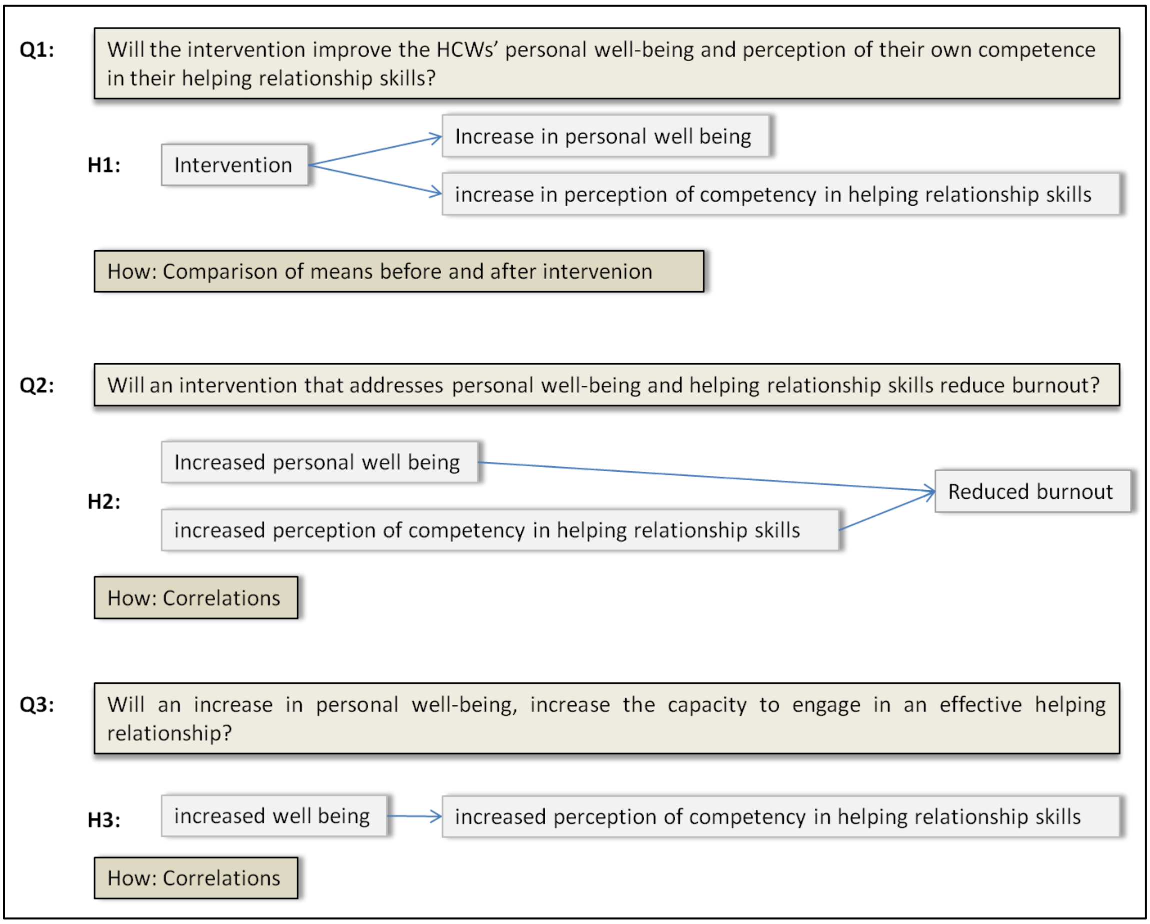


FIGURE 1 - HYPOTHESES

1.5 METHODOLOGY

A research study was undertaken with HCWs who cared for patients with a terminal condition in Portuguese health institutions in various parts of the country. Interventions were carried out within a therapeutic setting, with a limited amount of participants in each group and addressed both patient care and the emotional aspects of HCWs' fears of death and dying. The focus was on determining whether learning to cope with death anxiety, improving the quality of HCWs' personal lives, by investing in personal relationships and meaningful activities, and attaining a deeper understanding of patients' emotional and spiritual needs combined with better communication could reduce burnout in HCWs and improve the perception of their capacity to engage in an effective helping relationship with the patient and family. This was performed using a mixed-methods quasi-experimental study looking at these issues. The first part of the intervention on self-development was given by the author of this research and for this reason measures were taken to ensure unbiased results.

1.6 GENERAL OUTLINE OF THE THESIS

This thesis will start with a literature review that addresses how the general concept of burnout has evolved to date, followed by burnout specifically in end of life care, showing that a new perspective of burnout is needed for end of life care. The literature review ends with an analysis of interventions that prevent and reduce burnout in end of life care and concludes with the main features that need to be present in these types of interventions. It will then follow with a methods sections which will discuss the choice of the quasi-experimental design, describe the intervention used, discuss the size of the sample used and recruitment methods, describe the instruments used, how the data will be analysed and finally, how ethical issues were addressed. The results are shown in two separate chapters, the first showing the quantitative results, and the second the qualitative results which ends with a comparison of both. The thesis ends with a discussion of the results, followed by final conclusions and recommendations.

2. LITERATURE REVIEW ON BURNOUT IN HEALTH CARE WORKERS IN END OF LIFE CARE – MODELS, CAUSES AND INTERVENTIONS

CHAPTER OUTLINE

The purpose of this literature review is to build an underlying framework of burnout in end of life care, on which to base an intervention to prevent and reduce burnout in HCWs who care for patients with a terminal condition followed by an analysis of how this intervention should be designed.

The first section explains the methodology undertaken for the literature review.

The second section critically analyses the evolution of the concepts of burnout. For purposes of clarity, section 2.2 of the chapter ends with fig. 2 showing the main guidelines of how the concept of burnout has evolved, which will then be contrasted with fig. 5 at the end of section 2.4 which integrates other dimensions considered necessary for burnout in end of life care. Section 2.2 analyses different frameworks of burnout from 1974 to 2005 with a view to understanding how the dimensions and concepts of each framework have evolved and contributed to each other. The section is structured around the main concepts upon which these frameworks were built, which are personality, work environment, lack of control, meaning and existentialism, lack of coping mechanisms and compassion fatigue, as shown in fig 2.

The third section of the chapter focuses on burnout in health care workers with a special focus on end of life care and will look at the risk factors and consequences. The section has been divided into personal, professional and institutional factors. It ends with fig. 3, a synthesis of the causes of burnout in end of life care.

The fourth section highlights the need for a framework of burnout that provides the means to increase the internal congruence of HCWs who care for patients with a terminal condition by addressing their death anxiety and providing training that will help them provide an ‘exquisite’ quality of presence to dying patients. Fig. 5 shows what criteria need to be added for these frameworks to be adapted to burnout in end of life care.

The fifth section reviews the literature on interventions to prevent and reduce burnout in end of life care. Taking into consideration the findings of the previous sections of this chapter, it brings forth interventions that show the important aspects that need to be present in an intervention designed to help HCWs provide emotional and spiritual care to patients with a terminal condition with a high quality of presence albeit without losing their internal congruence. The section starts with an overview of how these training interventions began, followed by studies that showed the lack of education in death and dying and their consequences, and finally a critical analysis of existing interventions and their results. The interventions will be analysed according to the themes of self development in relation to death anxiety and life satisfaction followed by an analysis of teaching methods and techniques, and the format that best suit these types of interventions.

The chapter ends with a summary and a diagram showing a proposal of an intervention to increase the internal congruence and reduce burnout, based on the findings of the literature review.

2.1 METHODOLOGY OF THE LITERATURE REVIEW

An integrative review of the literature was performed. This has been defined as "a form of research that reviews, critiques, and synthesizes representative literature on a topic in an integrated way such that new frameworks and perspectives on the topic are generated. The body of literature includes all studies that address related or identical hypotheses" (University of Southern California, 2013).

Peer reviewed articles were researched using the on-line search engine from the University of Kent. The following subscription resources were used: Academic Search Complete, EBSCO, PsychINFO, psychARTICLES, PubMed. This was complemented by a systematic search through all palliative care journals available online from 2000.

The main terms searched individually or combined were: avoidance mechanisms, burnout, collusion, communication, conspiracy of silence, death anxiety, bad news, boundaries, courses, death, difficult patients, doctor, dying, education, end of life, ethics, existential, fears, grief, health care worker, hospice, interventions, job satisfaction, loss, meaning in life, nurse, oncology, palliative care, palliative sedation, self awareness, self development, team, teamwork, terminal care, terminally ill, training.

These terms were combined using the Boolean term "OR", or "AND". The Boolean search organizes the search by order of relevance according to the keywords. Some combination of keywords such as communication and palliative produced large amounts of articles (1238) and others such as existential fears produced smaller amounts (43). The articles were then scrutinized by reading the titles starting at the beginning and scrolling down and those considered most relevant in the opinion of the author were downloaded and saved. This procedure was stopped once the articles were no longer of interest. The abstracts of the downloaded articles were read and articles considered of interest for this study were saved in a separate folder for study. This procedure was performed at regular intervals from 2006 to 2013. The following were chosen for study:

- Burnout and job satisfaction: 181 articles
- Death anxiety: 37 articles
- Communication: 39

- Interventions (prevention of burnout/death anxiety and self development: 66
- Difficulties: 20
- Ethics: 45
- Palliative care organisation: 7
- Teamwork: 44
- Death studies: 19
- Methodology and research: 86

From the bibliography of these articles, several other articles were searched for in university libraries (older articles), google academic, asked for directly from the authors or requested at the Templelton library.

Several PhD theses were downloaded from the Templeton library online resources or asked for directly from the authors and books were obtained from the researcher's personal library, or borrowed from libraries and work colleagues.

2.2 EVOLUTION OF THE CONCEPT OF BURNOUT - MODELS AND DEFINITIONS

The concept of burnout as the reaction to stress and work leading to reduced ability at work was not used as an academic concept until 1974 and was initially introduced using a psychoanalytic approach, suggesting that it was more related to personality traits than the workplace itself (Freudenberger, 1974). The concept was extended by Maslach and from studies of how people coped with emotional arousal at work she suggested that the root causes were within the work environment (Maslach, 1978). There have been many publications on burnout (Kleiber & Enzmann, 1990) (Schaufeli, et al., 1993) but few are evidence based. Perlman and Hartman (Perlman & Hartman, 1982) summarized the literature until 1982, and of 48 articles published between 1974 and 1981, only 10% had empirical data.

The following sections show early research on burnout and how the concept developed, as different researchers added to previous models, or focused on burnout from different perspectives.

2.2.1 PERSONALITY TRAITS THAT CONTRIBUTE TOWARDS BURNOUT

Freudenberger observed workers in clinics (Freudenberger & Canter, 2001) and suggested that there are three types of workers particularly vulnerable to burn-out: the dedicated and enthusiastic worker who accepts too heavy a workload , the over-determined worker whose life outside work becomes unsatisfactory, and the authoritative worker who believes nobody other than themselves can work as effectively as them. (Freudenberger, 1975)

He described the concept of staff burnout in terms of the physical signs and the behavioural indicators - collapse, exhaustion or as extreme fatigue resulting from an excessive demand of energy, strength or resources (Freudenberger, 1974). The person is described as becoming rigid, stubborn and intransigent, blocking any progress and constructive change because the change requires more efforts to adapt, and as a result becomes cynical of their work and feels plunged into depression. He summarised these changes as the 4 D's: disengagement, distancing, dulling and deadness. (Freudenberger, 1980)

2.2.2 BURNOUT AND THE WORK ENVIRONMENT

Whereas Freudenberger focused on employees' personality and attitudes towards work as the root cause for burnout, Maslach focused on the work environment as the root cause, followed by subsequent defensive coping strategies leading to burnout. In her studies, she observed and interviewed several hundred people in the helping professions and argued that pointing a damning finger at character defects in the staff does not take into account the stresses in the work environment. Burnout was felt to be best understood in terms of the social and situational sources of job-related stresses rather than focusing only on the personal characteristics of the worker. (Maslach, 1976, 1978). In a similar way to Freudenberger, she used the term emotional exhaustion and detached concern as opposed to disengagement and distancing, and added the term dehumanization stressing the cynical and derogatory way in which clients or patients are treated as a result of burnout.

Burnout has continued to be developed as a concept with many different interpretations. Maslach claimed that the result was that "a concept that has been expanded to mean everything ends up meaning nothing at all" (Schaufeli, et al., 1993, p. 4). Further research resulted in a multidimensional model of burnout (Maslach, et al., 1997, p. 203) with a three-fold concept: emotional exhaustion, depersonalization and diminished personal accomplishment. These concepts were developed from the factor analysis of the Maslach Burnout Inventory (MBI), a questionnaire to measure levels of burnout, which was initially performed on a sample of 605 people from a variety of health and service occupations. The original 47 items were reduced to 25 items in 1981 and further research with 420 participants to obtain confirmatory data showed similar results. Further testing on the two samples combined (n= 1025) reduced the inventory to 22 items in 1986 (Maslach, et al., 1986). However, although the MBI has strong psychometric properties and is widely accepted internationally, it was validated by Maslach only within the USA in human services and therefore it cannot automatically be used in other settings and further testing or other psychometric analyses would be advised in other occupational or cultural settings (Schaufeli, et al., 1993).

Maslach & Jackson finally suggested a definition of burnout as: "a psychological syndrome of emotional exhaustion, depersonalization and reduced personal accomplishment that can occur among individuals who work with other people in some capacity."…. "burnout can lead to a deterioration in the quality of care or service provided….it appears to be a factor in job turnover, absenteeism and low morale…it seems to be correlated with various self-reported indices of personal dysfunction, including physical exhaustion, insomnia, increased use of alcohol and drugs, and marital and family problems". (Maslach, et al., 1997, pp. 192, 193). Emotional exhaustion was described as a depletion or draining of emotional resources and depersonalization as a development of negative, callous and cynical attitudes towards the recipients of one's services (Maslach, et al., 1997). It is an impersonal and dehumanized perception of recipients, rather than an impersonal view of the self. This is different from the psychiatric meaning where depersonalization is used to denote a person's extreme alienation from the self and the world (Schaufeli & Buunk, 1996).

The model suggested that burnout is caused by excessive demands, such as work overload, which in turn can cause internal conflicts, associated with lack of resources at work. Burnout, at the centre of the model consists of a combination of exhaustion, depersonalization or cynicism towards patients and reduced professional efficiency which eventually results in consequences for the workplace such as a reduction in performance, absenteeism and people leaving the service and employees becoming ill. The theory underpinning the model shows that burnout is an individual stress experience embedded in a context of complex social relationships and that it involves the person's conception of both self and others. Maslach et al. argue that to look simply at the stress component of this experience is not enough, because it ignores the two latter components of self- evaluation and relation to others. In this three-component model of burnout, reduced personal accomplishment reflects a dimension of self-evaluation, and depersonalization tries to capture a dimension of interpersonal relations. Both of these components extend beyond just being related to stress, (Leiter & Maslach, 2000).

Other authors have challenged the theory of Maslach. Shirom (1989) and Shirom et al. (2006) argued that burnout should not be restricted to individuals whose work requires large amounts of contact with people in need of aid, and therefore do not include depersonalization and efficacy in their core definition of burnout. Kalliath (2000) questioned the methodology of the validation process of the MBI and performed structural equation modelling studies on the MBI. Results showed a two-factor conceptualization of burnout consisting of emotional exhaustion and depersonalisation, where emotional exhaustion is the strongest factor. Personal accomplishment receved poor results. Demerouti et al (2001) questioned the wording of the items, because emotional exhaustion and depersonalization are all negatively worded items, and personal accomplishment are all positively worded. They argue that this may have cuased an artificial clustering of factors. Marques-Teixeira (2002), proposed an interactive system of burnout, which is slightly different from Maslach's model in that, as suggested by Shirom, it put the emphasis on emotional exhaustion as that which leads to burnout, and the other dimensions (depersonalization and diminished personal accomplishment) as a result. In this model, emotional exhaustion is caused by institutional demands, (such as work overload, hierarchical communication and role conflict) and individual demands, (such as high achievement expectations) and interpersonal relationships. Depersonalization occurs as a specific response to burnout in the form of a defensive coping strategy when other resources are not available (Marques-Teixeira, 2002). Diminished personal accomplishment and depersonalization is presented as a vicious circle: an employee who becomes cynical will feel less personal accomplishment, which can in turn increase the tendency to treat others in a depersonalised way (Marques-Teixeira, 2002). Although this model is not based on empirical research, it is helpful in understanding burnout as a dynamic process where the different components of burnout occur in different stages, starting with emotional exhaustion and stresses that it is not just influenced by outside factors, but internally, as depersonalisation aggravates reduced personal accomplishment and vice versa.

2.2.3 BURNOUT AND LACK OF CONTROL

This initial concept of burnout has been challenged and Karasek (1979) suggested that job demands in the work environment will only cause a strain on the worker if not counterbalanced with the correct amount of control (discretion, authority or decision latitude etc.) over their responsibilities. Karasek's research used a self reported quantitative cross sectional design, where job demands were measured through workload or role conflict (competing job-related role demands), through control as the ability to make decisions about how to complete job tasks, and strain was measured through physiological symptoms and cardiovascular disorder.

This research suggests that job demands are the psychological stressors at work such as interruptions, time pressures, workload, or how much concentration is needed, and the decision latitude is the amount of control employees have over their tasks and how those tasks are executed. This includes both skill discretion - the degree to which the job involves a variety of tasks, low levels of repetitiveness, occasions for creativity and opportunities to learn new things and develop special abilities - and decision authority - the employee's ability to make decisions about their own job, and their ability to influence their own work team and more general company policies. By crossing the dimensions of strain (demands) and latitude (control) one obtains four stress categories for jobs from High Strain Jobs where strain is increased by accepting more responsibilities but without the additional control; to Low Strain Jobs where there is as high control and low demand.

However, although there is empirical evidence showing that high job demands and low job control are predictors of psychological strain and illness (Karasek, 1979), support for the hypothesis that high control can moderate negative effects has been questioned (De Jonge & Kompier, 1997; Doef & Maes, 1999). Van de Doef & Maes showed that control only consistently acts as a buffer when associated with high supervisor support (Doef & Maes, 1999). This had been confirmed by previous studies which had shown that job control can effectively moderate the relationship between work demands and strain if accompanied by adequate levels of social support (Sauter, et al., 1989).

The success of this model was due to its simplicity, but this has also been a source of criticism. For example there are many types of job demands, not all of which have negative effects on workers, and workers may have a significant amount of control over some aspects of their work, but not others. It is also possible, that control may serve as a buffer for some types of people, but not for others. A social dimension was added to the model, resulting in the Job-Demand-Support model (Johnson & Hall, 1988) and Demerouti et al. (2000, 2001) presented the job demands-resources model. These models have received more consistent support than the job demands-control model, mainly because empirical tests have been careful to match specific forms of resources with specific forms of demands in predicting strains. (Kain & Jex, 2010). However, Kain & Jex suggest that to further reduce inconsistencies, longitudinal designs should be used, together with objective and subjective measures, a higher sample size, and a careful consideration of the types of demands and control that best match each other theoretically.

2.2.4 BURNOUT AND LIFE SATISFACTION

The model suggested by Demerouti et.al, (2000) presented life satisfaction (Rice, 1984) as an additional variable to the job demands-control model. Life satisfaction, - instead of job satisfaction - was included as an outcome of burnout, in order to test the hypothesis that work-related feelings might spill over to general life. This model was tested with 109 German nurses using structural equations modelling. The model discriminated between two conceptually different categories of working conditions, job demands and job resources. It was hypothesized that: (1) job demands, such as physical and cognitive workload, demanding contacts with patients and time pressure, are most predictive of exhaustion; (2) job resources, such as (poor) rewards and (lack of) participation in decision making, are most predictive of disengagement from work; and (3) job demands and job resources have an indirect impact on nurses' life satisfaction, through the experience of burnout (i.e., exhaustion and disengagement). Burnout was measured by the Oldenburg Burnout Inventory (OLBI), which consists of two factors, one ranging from exhaustion to vigor and the other from cynicism to dedication (Ebbinghaus, 1996; Demerouti, 1999), and which was validated in studies conducted in Germany, US and Greece (Bakker & Demerouti, 2008). The OLBI used the concept of disengagement - distancing oneself from one's work, and developing negative attitudes towards the work - rather than Maslach’s concept of depersonalization - distancing oneself emotionally from service recipients and developing cynical attitudes towards them. Job demands and resources were measured by a scale of 21 items, and life satisfaction was measured by the 4 items developed by Rice (1984). Results confirmed the strong effects of job demands and job resources on exhaustion and disengagement respectively, and the mediating role of burnout between the working conditions and life satisfaction. However, methodological questions were raised in relation to this model such as the use of self-reports which provide only one source of information which were not verifiable by other means. It has been suggested that multiple types of measures could be used to supplement self reports (Podsakoff & Organ, 1986). Furthermore, at the time of this study, the OLBI had only been validated in Germany and there are questions of the generaliability, but it has since been translated into English and validated with a sample of 2599 employees with positive results. Thus, it would seem to be a valid and validated alternative to the MBI, with balanced wording.

2.2.5 BURNOUT AND MEANING

The role of existentialism, which also plays a role in life satisfaction, was introduced into the concept of burnout by Pines & Aronson (1988). Citing Viktor Frankl (1963, p. 154) who said “the striving to find a meaning in one’s life is the primary motivational force in man”, she suggested that finding meaning in work can contribute towards the prevention of burnout (Pines, 2002). Similar to Maslach, this theory also regarded the work environment as the root cause for burnout, but focused on the work environment in terms of either supporting the goals and expectations of the worker, leading to a meaningful existence and reinforced motivation or not supporting them, leading to burnout and weakened motivation. The psychometric test associated with this model was tested on 3900 subjects, and proved to be internally consistent with α values ranging from .91 to .93. However, contrary to the MBI, factorial analysis did not reveal more than one burnout dimension (Schaufeli, et al., 1993). The instrument can therefore be considered a reliable and valid research instrument to measure exhaustion, but not depersonalization or reduced personal accomplishment.

2.2.6 BURNOUT AND AN IMBALANCE OF COPING MECHANISMS

Fawzy et al. (1991) presented an additional view, supplementing the views discussed above and made an important contribution by moving theories of burnout more firmly towards HCWs. He suggested a framework of burnout, where the emphasis is on coping mechanisms, following the theory of Lazarus & Folkman (1984). In this framework, burnout occurs in three stages: demands exceed resources in the first stage, causing stress in the form of a physical response of fatigue/exhaustion and an emotional response of tension/anxiety. This is followed by adaptive or maladaptive coping strategies, leading to a reestablishment of balance or not. Unsuccessful coping strategies lead to stage three where burnout may be manifested as cynicism, withdrawal, altered work patterns such as arriving late and leaving early, family conflicts, uncontrollable crying, excessive death watch (viewing death and disease, as well as life in general, as a battle which consumes all their time and energy) and substance abuse). This stage also shows the adaptive coping strategies the person needs to learn in order to restore balance, such as learning to apply principles of stress management, participating in support groups, seek help for substance abuse and seeking family therapy.

Although the model presented by Fawzy and colleagues is not structured around the 3-factor structure presented in Maslach Burnout Inventory in 1986 (Maslach, et al., 1997), it is clear that the concepts of emotional exhaustion, depersonalization and reduced personal accomplishment are present in the list of mal-adaptive resources (Fawzy, et al., 1991). This model was created as a practical aide for psychiatrists to recognise symptoms of burnout in HCWs and provide the necessary treatment

2.2.7 BURNOUT, COMPASSION FATIGUE AND VICARIOUS TRAUMATIZATION

Joinson (1992) introduced the concept of compassion fatigue as ‘a unique form of burnout affecting people in the care giving professions’ and by Figley (1995, p. 7) as “natural and consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other – the stress resulting from helping or wanting to help, a traumatized or suffering person”. The terms have been used interchangeably. For example, Keidel (2002) referred to compassion fatigue when referring to a family’s primary caregiver, and to burnout when referring to hospice care staff and highlighted in both cases the need for heightened awareness, as these syndromes are difficult to recognize. Compassion fatigue is a stress response that is sudden and acute and can be defined as a physical, emotional and spiritual fatigue or exhaustion that takes over a person and causes a decline in his/her ability to experience joy or care for others. If not recognized and treated, it can interfere with the ability to give quality nursing care that is safe and effective, can cause physical and emotional exhaustion, and result in depersonalization and an inability to nurture. (McMullen, 2007)

It has been argued that people with a higher capacity for empathy are more vulnerable to compassion fatigue (Figley, 2002). This view would be contested within the field of psychotherapy, where empathy is regarded as the capacity to enter the world of the other, correctly understand their feelings and try to convey this back to the person, thereby promoting growth and change. This capacity howver, must be accompanied by congruence on behalf of the HCW, enabling him to be fully engaged while with the person, but able to return to their own world afterwards (Mearns & Thorne, 1988) and thereby reducing the risk of compassion fatigue.

Thus, contrary to the view of Figley (2002) it would seem that performed correctly, empathy would be a source for personal fulfilment rather than compassion fatigue. An example of misused empathy is shown by Valent (2002) who suggested that compassion fatigue may stem from the personal needs of HCWs who use the relationship with the patient for their own needs, rather than being centred on the patient's needs.

The term vicarious traumatization has also been used with HCWs subject to witnessing traumatic situations with patients, It is has been defined as "negative transformation in the therapist's (or other trauma worker's) inner experience resulting from empathic engagement with clients' trauma material" (Pearlman & Saakvitne, 1995, p. 151). This implies that there is permanent disruption in the HCWs', cognitive schema. It would seem therefore that unlike compassion fatigue where support interventions and factors such as hope and resilience can help the HCW return to their normal condition (Simpson, 2004), vicarious truamatization has more permanent effects. This suggests that compassion fatigue may precede vicarious traumatisation. However, as burnout occurs for various reasons other than witnessing traumatic events, such as organizational characterisitics (Schaufeli & Enzmann, 1998), it is not clear whether burnout is a precondition for compassion fatigue and subsequently vicarious traumatisation, or a consequence.

A review of the literature shows the complexity of these concepts of occupational stress, and a lack of empirical evidence to support a theoretical framework (Thomas & Wilson, 2004). Further research is needed in this field, to understand the relationship between HCWs and patients/families and how this contributes towards compassion fatigue and vicarious traumatisation, and also, to understand the role of the individual charactistics of the HCW such as resilience and organizational factors in increasing or decreasing compassions faitigue. Further research is also required to establish where compassion fatigue, vicarious traumatisation and burnout would stand on a scale of occupational stress, as to date, it is not clear whether these concepts can co-exist or influence the onset of each other.

2.2.8 THE MEDIATION MODEL OF BURNOUT: A SYNTHESIS

Prior research focused mainly on the impact of the work environment on how burnout is experienced, and less on the role of burnout in mediating the relationship between the work environments and important work related outcomes (Leiter & Maslach, 2005). To improve their three-component model of burnout, Leiter and Maslach introduced a further change with the introduction of six areas of work life in an organizational context where, rather than focusing individually on the needs of the organisation or the employee, the aim was to find a way for the employees and the organization to establish a viable and enduring working relationship and to understand how this impacts on employees' perception of the organization changing for better or for worse.

Further research was performed which resulted in a new model of burnout. This model was created from the results of the analysis of three questionnaires to 602 full-time university employees and 2009 full-time hospital employees. The questionnaires used were the MBI, (Schaufeli & Buunk, 1996) the Areas of Work Life Scale (Leiter & Maslach, 1999) and a questionnaire designed to evaluate employees' perception of change. The model was tested using a structural equation modeling program (Bentler, 1995) in order to consider the overall fit of the model and whether all the hypothesized paths were statistically significant. Confirmatory factor analysis was also performed on all the measures used. The analysis also considered the extent to which the burnout-engagement continuum mediated the relationship between the six areas of work life with the outcome of evaluation of change. The results supported the proposed mediation model and the complex relationships were replicated strongly in both populations.. A limitation of this study is that it is based on self report data on a cross-sectional research design rather than an experimental design. (Leiter & Maslach, 2005)

The strength of this model is the way in which it brings forward concepts that were unclear in previous models, making burnout easier to understand and prevent. The six areas are: workload, control, rewards, community, fairness and values. Leiter and Maslach propose that the greater the perceived gap between the person and the job, the greater the likelihood of burnout; conversely, the greater the consistency of these six areas within the person's conception of their job, the greater the likelihood of engagement with work. (Leiter & Maslach, 1999). These six areas were described as follows (Leiter & Maslach, 1999):

Workload: With an excessive workload to be done in a given time, and no time to recover, individuals may become vulnerable to exhaustion. Work overload may vary with the type of work and the way people understand their work, for example if the workload is perceived as too heavy to be able to provide quality care.

Control: Individuals need to have control over choices and decisions to solve problems, and to contribute to the fulfilment of their responsibilities. A lack of control to fulfil these responsibilities can occur due to multiple authorities with conflicting demands or incongruent values, or an absence of direction at work or when workers do not have the autonomy to shape their work setting in a manner consistent with their values.

Reward: A meaningful reward system acknowledges contributions to work and provides clear indications of what the organization values. People experience a lack of recognition, both financial and social, as devaluing their work and themselves, but may also experience strain if contributing less than their colleagues with similar rewards.

Community: People thrive in communities characterized by support, collaboration, and positive feelings which help them cope with demands. There are different types of support within the organization. Leiter (1991) showed that supervisor support is more consistently related to the exhaustion factor, whereas co-worker support is related to accomplishment or efficacy. However, the role of social and family support outside the work environment was not considered.

Fairness: This is characterized by the extent to which the organization has consistent and equitable rules for everyone, particularly in the way that the administrative leadership is perceived. When there is mutual trust among workers and people show consideration for each other, fairness within the organization is normally present.

Values: When organizational and personal values are congruent, successes are shared. Mismatches occur when differences exist between an organization's values and the values of its staff, or if the organization does not practise its stated values, causing disruption in relationships and loss of motivation. A values mismatch can cause a reduction in involvement, because workers are not confident their efforts are making a contribution towards what they believe in. Work with no meaning leads to indifference, cynicism and depersonalization.

As in Karasek and Teorell's model (1990), control plays an important role, but rather than having a direct link to burnout, the mediation model shows that part of the relationship of control with burnout is mediated through workload and another part through other areas of work life. This model has three phases: Firstly, the conditions that lead to burnout: Control is related to all areas of work life: workload, reward, community and fairness. This then leads to the standard pathway of the 3 dimensions of burnout: Workload has a direct path to exhaustion, values mediates the relationship of all work life areas (except for workload) with the three dimensions of burnout and exhaustion predicts cynicism, which in turn predicts lack of efficacy. Finally, these three dimensions predict the outcome of evaluation of change.

The final model seems to be a good synthesis of the majority of the models reviewed in this section, but it does not seem to take into account life satisfaction and existential well-being. Section 2.4 will analyze how this is an important part of a framework for burnout in health care workers who care for patients with a terminal condition.

2.2.9 SECTION SUMMARY

Theories of burnout have evolved since the concept first emerged with Freudenberger and different researchers have capitalized upon previous explanations, introducing new core concepts. After Freudenberger focused mainly on personality, Maslach focused on the work environment; Karasek on lack of control; Demerouti on life satisfaction; Pines on meaning; Fawzy on coping mechanisms and finally, Maslach et al introduced the mediation model of burnout. This model draws upon these different models, but shows the process of burnout as an ongoing dynamic negotiation that requires continuous dialogue throughout the organisation to create a viable and enuring relationship between the organisation and the employee and it also takes into consideration the employees' perception of the organization changing for better or for worse. These different theories help to identify and better understand the responses to a stressful caring environment and the risks attached for the individuals affected. It should, however, be acknowledged that extensive research has been performed over the last 40 years by different researchers with an overlapping of concepts and terminology that can be confusing. The following figure strives to summarise these findings in a simplified way. (fig.2). A more detailed synthesis of these theories in the form of a diagram can be found in Appendix 1.

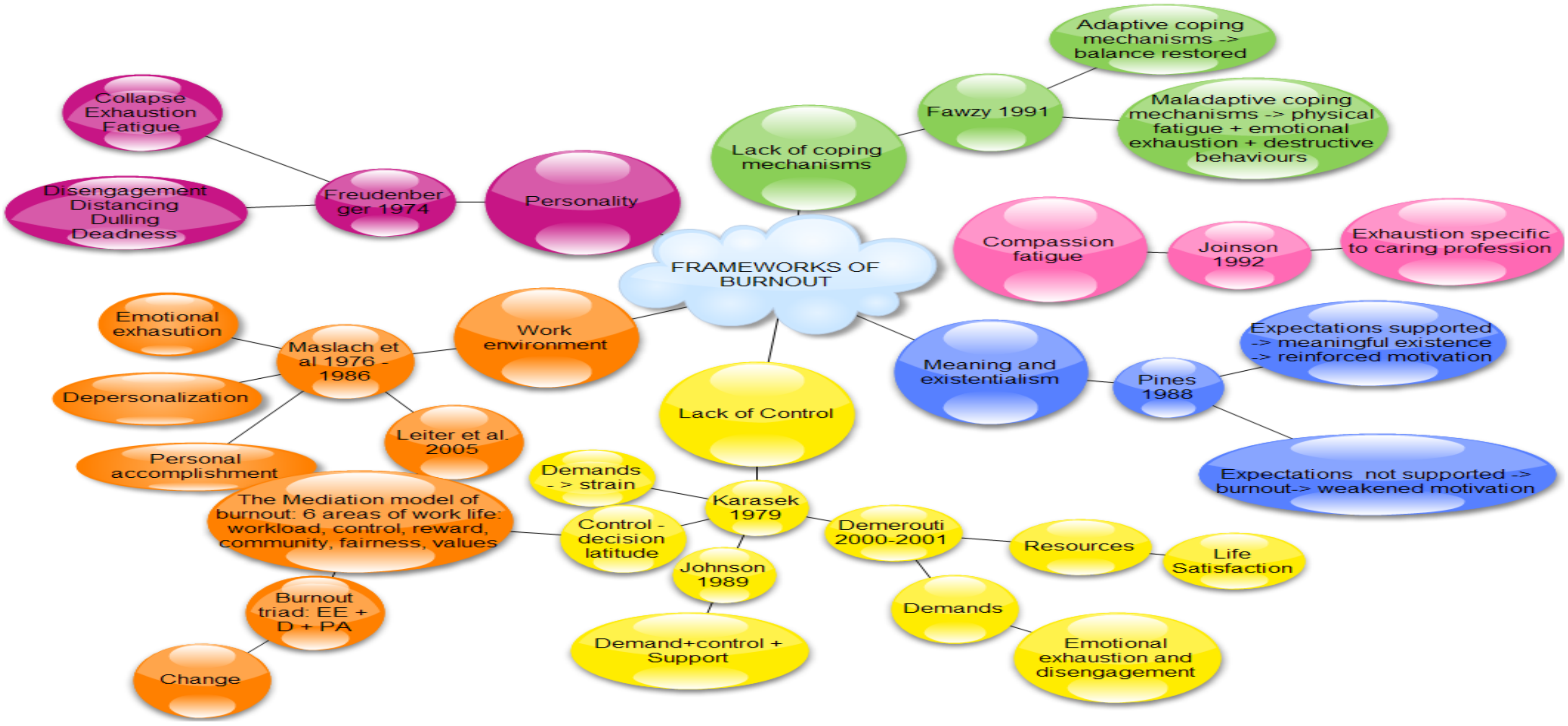


FIGURE 2 - SUMMARY OF MODELS OF BURNOUT

2.3 CONTRIBUTING FACTORS AND CONSEQUENCES OF BURNOUT IN END OF LIFE CARE

Early studies on causes for burnout in HCWs who care for patients with a terminal condition were carried out by of Mary Vachon (1977) who undertook eight sessions of discussion groups as a means to understand burnout in nurses working in two cancer units. The methodology used was non directive, and gave HCWs the liberty to talk freely about what they felt contributed towards burnout. The main causes of burnout that emerged were related to personal, professional and organizational issues. These areas will be elaborated on as key distinctions in three main sections in this chapter.

In personal issues, Vachon includes aspects such as having to cope with patient's suffering, grieving their subsequent death, and issues such as how the role and the work environment affects home life.

In professional issues, Vachon includes excess workload which may interfere with giving quality time to the patients, interpersonal relationships, such as conflicts or communication problems with colleagues and other departments, and feelings of isolation, especially with HCWs in charge of others, and difficulties within the helping relationship with the patient and family.

In institutional issues, Vachon mentions lack of social support, exhaustion due to lack of staff and working overtime/ not enough vacation, excess bureaucracy, lack of training and financial pressures to lower costs, which may also interfere in patient care.

Further research with 600 caregivers to the critically ill, dying and bereaved, 100 of whom were in hospice/palliative care, showed that of the above causes, almost half of the stressors reported (48%), were related to the work environment (Vachon, 1987). This is similar to the findings of Maslach (1976, 1978).

2.3.1 PERSONAL FACTORS AND CONSEQUENCES

Leading on from Vachon's work and with a focus on HCWs, the chapter will now consider the effects of personal factors and consequences in more detail. Personal difficulties will be considered in terms of death anxiety and feelings of helplessness when faced with the limitations of medicine. These difficulties may result in personal incongruence when in the presence of a dying patient. The need for personal development as a means to cope with these difficulties will be shown throughout this section.

Risk Factors

There are a number of articles in recent times that focus on the relationship between burnout and health care workers who care for patients with a terminal condition, studying different variables. This highlights the complexity and often contradictory nature of the findings, which makes addressing them in a homogenous way difficult.

Burnout: Age, Years of Experience

Studies on the relationship between burnout and age show that HCWs under 30/40 years old, and consequently those with less work experience, have higher risks for burnout (Maslach, et al., 2001). These results are consistent with the findings by Vachon (1997), as she suggests that younger people are more prone to stress and have fewer coping strategies, which in the long run is a risk factor for burnout. Also consistent with these findings were studies on HCWs in Turkey which showed that emotional exhaustion and depersonalization were significantly higher in HCWs under 29 years of age than in the older age groups (Alacacioglu, et al., 2009). However, Maslach calls for caution in her results, as it may be that those over 30-40 years who have been evaluated are the more resilient survivor HCWs who did not leave their particular job earlier on. However, one may question whether the older employees in Maslach's study had already suffered from burnout when younger, and have now learned to cope.

Other studies however, showed contrary findings: an Italian study, with 100 oncology nurses, revealed that high levels of emotional exhaustion were found in nurses older than 40 with a working seniority of more than 15 years (Quattrin, et al., 2006) and a French study showed that emotional exhaustion was mainly observed in older professionals and those who had been working in oncology for long periods (Lissandre, et al., 2008).

Cherniss (1992) published the results of a 12 year long-term study on people working in the care sector (public service law, public health nursing, high school teaching and mental health), on the relationship between burnout in the first year of work and a decade later. Results showed that subjects who suffered more burnout earlier in their careers were less likely to change careers and were more flexible in their approach to work. The results suggested that early career burnout did not seem to lead to any significant, negative, long-term consequences. However, burnout occurring later in the career might have more serious long-term effects. Quattrin et al. (2006) who found higher levels of burnout in HCWs over 40, suggest this may be due to a possible change in education: whereas previously, young students were not given much preparation in coping with death, this is now changing and students do receive support and education in their training and this leads to less burnout in younger HCWs.

Lissandre et al. (2008) found that reasons given for burnout in older HCWs who had been at work longer (although the limit set was only 'over 5 years') were a reduction in the quality of their life, bad organization at work, difficulty in getting advice from doctors, patients being admitted in a disorganised fashion, and not being appreciated by doctors.

Maslach, Schaufeli and Leiter (2001) pick up the theme of education, and reported that those with a higher level of education report higher levels of burnout than less educated employees, although this may also be related to higher job responsibility and stress, and job expectations.

Burnout, Gender and Marital Status

Maslach, Schaufeli and Leiter (2001) found that gender does not appear to be a strong predictor of burnout, although studies seem to show a higher level of cynicism in men and a higher level of exhaustion in women. However Vachon (2000) claims that female physicians who may have to balance work and home commitments may be at increased risk for burnout.

The relationship between burnout and marital status showed that unmarried people, especially men, seem to be more prone to burnout than married people, and single people more than divorced (Maslach, et al., 2001). Results from a Turkish study were consistent with these findings showing that emotional exhaustion and depersonalization were significantly higher in single physicians compared with married physicians (Alacacioglu, et al., 2009). These findings therefore mirror research on the protective factors of family life (Coatsworth, et al., 2000). Vachon (2000) also found that being single, rather than married with children is a risk factor.

Burnout and Personality

Similar to Freudenberger (1974), Piedmont (1993), found a long-term relationship between burnout and personality, where personality accounted for a significant amount of the variance in the burnout scores: strong correlations were found between burnout (emotional exhaustion and depersonalization) and neuroticism (anxiety, hostility, depression, self-consciousness, impulsiveness and vulnerability). This suggested that HCWs who were anxious, depressed and unable to deal with stressors were those who experience emotional exhaustion and depersonalization.

Death Anxiety

Death anxiety appears to be an issue in end of life care. The following subsections condense the different aspects of death anxiety into three different areas.

Death Anxiety, Personal Relationships and Meaning in Life

Death anxiety has been defined as an experience of everyday life, rather than an immediate threat, involving components such as: anticipating one’s self dead, fear of the process of dying and fear about the death of significant others (Neimeyer, 1994, 2003). It has also been defined as a negative emotional reaction provoked by the anticipation of a state in which the self does not exist (Tomer & Eliason, 1996).

Neimeyer’s view seems to be more encompassing because in end of life care, HCWs are not just dealing with an abstract concept of death itself, but with patients who are still alive but facing death and through daily care, become part of HCWs’ lives. Their particular issues may cause anxiety within the HCW, particularly if these are similar to issues in their own lives. This was confirmed by studies undertaken by Tomer and Eliason (2000, 2005), who tested a comprehensive model of death anxiety. This model found that death anxiety is composed of past-related regrets, future-related regrets and another concept related to one’s sense of coherence: how one understands, copes with and attaches meaning to an experience (Antonovsky, 1987). Past and future regrets are related to the perception that one has not fulfilled, or will not be able to fulfil one’s life goals.

In this sense death anxiety is not only about immediate threats to life, but about the whole process and how this is understood and rationalized in the individual context. HCWs who care for patients with a terminal condition may be reminded daily of life’s finite nature and consequently of these existential issues and Jones (2009) claims that HCWs in palliative care often question their own values and reassess the meaning of their own lives and unresolved issues. Vachon (2000) also called attention to the fact that unresolved stressful life events can be a source of vulnerability towards burnout. For example, Neimeyer (1994) has suggested that those with a strong fear of death may be unable to live life to the full, particularly finding difficulty with close relationships as they may fear the death of those they love. By choosing to protect themselves from such thoughts, either by keeping their distance from patients or ignoring these issues, there is a risk for their emotional well-being in the long-term. This leads to a further risk, as suggested by Zundel (1979), that when death finally arrives, and one becomes aware that life could have been something grand, it is too late and death appears to be a bottomless pit causing anxiety and frustration because there is no time left to live again. However, on the contrary, resolved stressful life events can bring strength to the workplace as will be discussed below.

Florio et al (1998) draws attention to a different area of personal issues when HCWs may overreact at home due to stress at work or conflicts between work and family responsibilities.These factors therefore could be considered to be significantly influential on the manifestation of burnout in HCWs and there is therefore the need to address this issue as a contribution to burnout at a deeper level.

Death Anxiety, Physical Change and Dependency

When people age without serious illness, physical incapacity increases slowly with more time to adapt to loss of function and dependence on others. Expectations in life change with age as Maurice Chevalier once said: “Old age isn’t so bad when you consider the alternative.” (Chevalier, accessed 2012). HCWs who care for patients with a terminal condition, are confronted daily, not only with normal ageing symptoms, but with seriously incapacitating physical degradation in people of all ages associated with unpleasant tasks, such as wound care and coping with urinary and faecal incontinence (Fawzy 1991, Berthon, et al., 1996; Payne, 1998; Lawton, 2000; Mercadier, 2002; Pereira, 2011). This may be associated with uncontrolled pain, loss of dignity and psychological and spiritual suffering, which can be disturbing for HCWs (Keidel, 2002; Connelly, 2009). Raphael (1984) cited in Abdel-Khalek (2002) argues that this is a different aspect of death anxiety that comes in the form of fear of pain, mutilation, the unknown, annihilation of self, the process of dying with loss of function and of becoming dependent on others.

Berthon et al. (1996) using questionnaires and open ended questions with 186 nurses working in oncology departments in several different hospitals in France found that these issues are important as there was a strong correlation between professional stress and caring for bedridden patients who are unable to move and who suffer from faecal and urinary incontinence, which affect the olfactory senses of the HCW. The intensity of stress and the process of burnout increased when patients manifested strong pain. The sample was one of convenience so it could be argued that there was a bias in the population involved.

Other studies showed that even when palliative care is available, terminal illnesses can also cause ugly physical deformities such as facial disfiguration (Pereira, 2011) and ‘unbounded bodies’ such as uncontrolled urinary and faecal leaking, and fungating tumours, associated with unpleasant smells (Lawton, 2000), which are difficult to live with, both for the patient and the carers. These experiences are a vivid reminder of HCWs’ own vulnerability and mortality, often before they are emotionally ready to accept it, which can result in increased discomfort when in the presence of these patients.

Mercadier (2002) interviewed 30 nurses in France using grounded theory methodology enriched by interviews with patients to gain access to issues that would not voluntarily be mentioned by HCWs, thereby enriching the grid of questions whilst interviewing the nurses. This showed that coping with degrading bodies may be hard to accept by HCWs regardless of age. The younger, for example, are still attached to youth and beauty and the older nurses may feel that they are seeing the possible changes they will encounter in their own lives in the not too distant future. Nurses gave graphic descriptions of patients and the emotional and physical effect this had on them, thus reinforcing the concepts of coping with 'unboundedness' as described by Lawton (2000).

Payne (1998) interviewed 23 hospice nurses in the UK to assess death anxiety. The results support these ideas, as nurses commented on their difficulty in coping with unsightly disfigurations such as descriptions of a patient with eyes and tongue that were protruding. This study is similar to that of Mercadier (2002) in that they both included a small sample of participants and both used content analysis of interviews. However, Mercadier's study provides more information on this issue, as it focused specifically on HCWs' emotional relationship with the patient's sick body whereas Payne focused on death anxiety in general.

There are several ways to react to this kind of discomfort and research shows that death anxiety may lead to avoidance behaviours (Neimeyer, 1994). Negative conceptions of the elderly may create a fear of growing old and this may affect quality of care, such as mistreatment and a reluctance to work with the aged (Bennett, 1976). In contrast to this, within palliative care services, there is a general approach to encourage HCWs to show 'exquisite' empathy, defined as "highly present, sensitively attuned, well-boundaried, heartfelt empathic engagement" (Kearney, et al., 2009, p. 1160). This may help the HCW to relate to the person within the sick body instead of allowing themself to become overwhelmed by the patient's deteriorated physical appearance which may in turn interfere with their capacity to engage in an effective helping relationship. This can be achieved by specific education in palliative care and increased emotional support.

Lawton (2000) proposes an alternative form of coping with physical degradation that considers the contrast between the generational spectrum. She reflects that society today promotes the concepts of being self sufficient, productive, physically beautiful and fitness as the aim of life, and this leads people to consider themselves a burden to others when this is no longer possible, particularly when they become incontinent. However, Lawton (2000, p. 142) argues that parents do not consider babies a burden and are not nauseated by their bodily fluids, whereas for adults, incontinence and an 'unbounded body' may be seen as offensive and unpleasant. Leloup & Hennezel (2008) provide further support to these theories as they claim that with the right training in spiritual care, it is possible for HCWs to alter their perceptions of an adult patient, and thus in spite of offensive smells and sights, appreciate instead their inner beauty in the same way that they may cope and appreciate babies. Interventions to assist HCWs in overcoming stresses are considered in more detail in section 2.5.

It may be important for HCWs to be given the opportunity to reflect on these issues, and to find a space where they can see themselves as more than just a fully functioning body and that their value as a person is not limited to the physical state of their body. This may help them to reduce their anxiety regarding the prospect of their own future physical degradation as well as their uneasiness with the patient. (Jones, 1998).

Death Anxiety and Unresolved Grief

Caring for a patient with a terminal condition, or for terminally ill children can remind the HCWs of someone close to them, or of their own children (projected losses) or of the death of a loved one who perhaps died of the same illness (Payne, 1998), and of whose death they have not yet overcome (unresolved grief) (Williams, et al., 2005). This may create problems with boundaries and influence neutrality (Friedrichsen & Milberg, 2006). Nasrallah (2009) referred to boundaries as the ideal ethical, physical, and emotional constraints that create limits within a relationship and provide safety when inequality exists between two individuals.

Hennezel (1998), however, argues that having a close and intimate relationship with patients with a terminal condition should not be discouraged, but that one needs to create the *right distance.,* This assumes that the HCW is sufficiently self aware and congruent to be able to accept the psychological and physical intimacy of exchanges and simultaneously recognize their own fears, failures and vulnerabilities.

For this kind of acute sense of self-awareness to be achieved, self-development is essential, and a rationale of intervention to address needs will be considered later.

Difficulty in Accepting the Limitations of Medicine

Different approaches exist towards the limitations of medicine. Outside the sphere of palliative care, HCWs often experience difficulty in accepting the limitation of the care they can provide, as they feel that they have been trained to find answers and solutions to patients' problems. It is particularly difficult for doctors, because of the onus of responsibility they are expected to carry (Williams, et al., 2005), and having to tell a patient that curative treatment has failed can make doctors feel as though they themselves have failed and have let the patient down, with consequences for their own sense of personal value and adequacy (Currow & Hegarty, 2006). This can also cause feelings of guilt (Kearney, et al., 2009), which can contribute towards burnout. For example, frustration and sense of failure was the most frequently chosen description of burnout in oncology physicians (56%) (Whippen & Canellos, 1991). Nurses are also affected when these doctors, as a result of their incapacity to cope with this sense of failure, may avoid the patient. Nurses who understand palliative care know what can be done to alleviate suffering, yet are obliged to observe unnecessary suffering due to inadequate response from doctors (Florio, et al., 1998; Fillion & Saint-Laurent, 2003). These limitations, which are seen as unnecessary, are particularly difficult to accept.

When HCWs are confronted with difficult questions such as “Do you think I am going to die?” they may also see the limitations of medicine as they do not have an answer that will make the patient feel better and this can leave them feeling helpless. Moreover these questions may also come unexpectedly, when HCWs are unprepared (Hennezel, 1998).

In contrast to this, within palliative care services the emphasis is on the holistic care of the patient and family, rather than cure of the disease itself, and this approach, within the wider interdisciplinary team, may allow the HCW to cope with the issues they face.Twycross, (2005) uses the expression ‘to die healed’ to explain that inner healing may occure even if a cure may not be possible.

Bereavement and Compassion Fatigue

The concept of compassion fatigue was defined in the previous section. This section approaches how it is manifested in HCWs who care for patients with a terminal condition. Whereas burnout results from stresses that arise from the clinician's interaction with the work environment (Maslach, et al., 2001), compassion fatigue evolves specifically from the relationship between the clinician and the patient causing "emotional pain that has lead helping professionals to abandon their work with traumatized persons (Figley, 1995, p. 7). For example, feeling grief over a patient's death and subsequently not having time to grieve before having to carry on working without a break may lead HCWs to feel they have nothing left to give, leading to compassion fatigue (Fawzy, et al., 1991; Florio, et al., 1998; Vachon, 2000; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008). Kearney et al. (2009) argues that clinicians who care for dying patients are at risk of both burnout and compassion fatigue and considers prevention factors, such as learning healthy ways of empathising and practising self awareness.

Abendroth and Flannery (2006) studied the risk factors for compassion fatigue with 216 nurses from 22 hospices in the state of Florida with a non-experimental descriptive design using cross-sectional data and descriptive and inferential statistics. Trauma, anxiety, life demands, and excessive empathy (leading to blurred professional boundaries) were key determinants of compassion fatigue risk. The results showed that participants were at moderate to high risk for compassion fatigue (M= 13.6, SD= 6.59, where minimum is under 7, moderate is from 8-17 and high is over 18). The risk was exacerbated when nurses exhibited a lack of self-care, and an inability to debrief after a traumatic event diminished internal coping mechanisms, and increased vulnerability. In comparison, a study using the same instrument, but with nurses from a cancer centre did not show much difference: levels of compassion fatigue were only slightly higher (15.2, SD=6.6) (Potter & Deshields, 2010). However, a study by Holland and Neimeyer (2006) found that HCWs with a greater number of hours in end of life training tended to experience reduced physical fatigue and cognitive weariness, but did not experience less emotional exhaustion. In other words, training may increase levels of self-efficacy and confidence, but the change is on an intellectual level; it does not give emotional competencies. This study found that daily spiritual activities had a positive impact on emotional exhaustion.

These difficulties related to death anxiety, limitations of medicine and bereavement and compassion fatigue may also have consequences for the HCW, as described in the following section.

Personal Consequences of Burnout

Previous sections have outlined the consequences of burnout in terms of impact on work satisfaction and emotional exhaustion. Burger (1995) introduces intellectual, psychosomatic and behavioural symptoms. The intellectual issues encompass a loss of sense of priority and paralysis of thought processes resulting in lack of organisation. The HCW may then work extra hours trying to make up for lost efficiency, resulting in fatigue, which may aggravate feelings of intellectual regression.

Psychosomatic symptoms can range from painful physical symptoms, such as inner tension, sluggish or abdominal breathing, epigastric heaviness and asthenia to pathological states such as headaches, digestive problems, colds, influenza and sleep disorders.

Behavioural symptoms include increased absenteeism, which can be combined with working overtime to compensate for lost efficiency and substance abuse (mostly alcohol) is also common, as shown by Finlay (1989). A study with 49 medical directors and 36 matrons of British hospices showed a tendency to self medicate with psychotropic medications in 10% of hospice medical directors and 10% of matrons, with hypnotics being used in 29% of medical directors and one matron and alcohol being used to relieve stress by one third of both groups. Suicidal thoughts of more than 2 weeks duration were present in 16% of the medical directors and 3% of the matrons and 11% of the matrons and 8% of the medical directors acknowledged suicidal thoughts of less than two weeks duration (Finlay, 1989).

Keidel (2002) however, cautions towards the need to differentiate between symptoms of burnout and depression, as different interventions are required for each. A table with these differences can be found in her article.

These personal difficulties may also have professional outcomes and affect the way the HCW communicates with the patient and family and interacts within the team.

2.3.2 PROFESSIONAL ISSUES

This section will address professional issues that the literature has identified as stressful for HCWs in end of life care. These are issues related to communication, such as giving bad news and dealing with difficult patients and teamwork.

<u>Communication</u>

As part of the Person Centred Approach, good communication is essential and this will be more likely when the HCW feels congruent in the relationship with the patient or family allowing him to be genuine and authentic, when there is the ability to accept the other without judgment, (unconditional acceptance) and when empathy rather than sympathy is present. These have been described as the core conditions of a helping relationship (Rogers, 1951).

This section considers how communication may fail and avoidance behaviours may develop when the HCW feels incongruent within the relationship and is thus unable to be genuine, together with factors that can reduce the HCWs' capacity for unconditional acceptance, reinforcing the need for training and self-development and the importance of empathy both for the patient and the HCW.

Giving Bad News and Avoidance Behaviours

The communication of bad news and difficult issues is not easy and staff may be reluctant to break bad news or answer questions that may imply the patient's death (Alexander & Klein, 2000). It is a task that most often falls upon physicians who may feel unable to control the conversation and the patient's reactions. Difficulties may involve dealing with the patient's denial, or the families' collusion with the patient and not having the knowledge to answer certain questions, such as "How long do I have to live?" (Friedrichsen & Milberg, 2006). It has been suggested that these difficulties may be accompanied by their own thoughts related to existential matters, such as being reminded of their own mortality, or they may be viewing themselves as a failure and feeling guilty for not having done enough, as previously discussed (Kearney, et al., 2009). They may also be finding it difficult to remain neutral because they may have become emotionally involved (Payne, 1998).

Most of these difficulties concern the acceptance of loss of control, which as mentioned in the mediation model of burnout (Leiter & Maslach, 2005), plays a major role in the prevention of burnout. However competent the HCW may be, controlling all aspects of the patient's outcome is not possible and this may create feelings of insecurity. It would seem therefore that it is not enough to just learn the best way to give bad news on a technical level, but HCWs need a much deeper preparation at an existential level to help them deal with these issues with inner calmness (Hennezel & Leloup, 1997). This calm state of mind may be passed onto the other person as described by Hennezel and Leloup in the Six Stages of Dying (Hennezel & Leloup, 1997) and this may in turn help them cope with the bad news with more confidence.

These difficulties may result in defensive behaviours by the HCWs, such as 'blocking' which involves changing the subject; 'conspiracy of silence' when information is withheld in order to protect the patient, the family or both; 'lecturing', involving imparting large amounts of technical information without discussion and premature reassurance when reassuring patients' concerns too quickly before exploring and understanding their concerns (Back et.al., 2005).

These different avoidance behaviours may relieve the HCW at the time, but may ultimately contribute towards feelings of guilt for not having supported the patient's real needs, as discussed by Kearney et al. (2009) and these negative feelings may contribute towards an increase in burnout. It could be argued therefore that HCWs would benefit from personal development to become aware of the avoidance mechanisms used with patients and to reflect on what causes their discomfort.

Dealing with the 'Difficult Patient'

There seems to be a consensus that dealing with angry, aggressive and demanding families is challenging for HCWs (Florio, et al., 1998; Vachon, 2000; Keidel, 2002; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008; Pereira, 2011). However, the actual meaning of a 'difficult patient' in the literature can change according to different settings. Elder, Ricer & Tobias (2006) interviewed 102 physicians on what they considered to be a difficult patient. This showed the focus to be on the patient's personality, such as patients wanting to stay within the sick role, demanding, noncompliant, non-appreciative and manipulative patients, or on certain medical problems such as patients with multiple problems and complaints, difficult diagnoses, patients who just came for medication, or those in chronic pain or with complicated psychiatric problems.

In end of life care, recent studies seemed to focus on medical conditions related to the advanced stage of the disease, such as psychosis, disinhibition, and severe anxiety (Peteet, et al., 2011) rather than on negative aspects of their personality. However, Pereira (2011) undertook an in-depth study on burnout in palliative care using grounded theory which raised the dilemma HCWs have when caring for a patient who causes conflict, or with whom they have difficulty establishing a relationship. The study stressed the importance of the HCWs being able to admit their difficulties and the team being supportive enough to help them or eventually put someone else in their place. Kübler-Ross (1970) showed an emotional aspect of a difficult patient in her description of the five stages of grief, such as coping with anger, fear, defensiveness and sadness/depression. Even though these emotions may be attributed to the patient's circumstances, rather than to their personality, it could be argued that they may still affect the HCW in several ways: HCWs may be the recipient of the patient's anger and defensive attitudes, and may absorb these negative feelings if they do not have appropriate training to cope with them, or they may feel helpless when facing the patient's fears, sadness or resignation/apathy.

Hull & Broquet (2007) argued that rather than just considering patient aspects, the physician and the situation also needed to be considered when confronted with a difficult patient. Fatigued, arrogant or defensive physicians can contribute towards a 'difficult patient' as can the situation, such as language difficulties, or lack of privacy when talking to the patient. In palliative care however, Crawford and Price (2003) stressed the need to also focus on the team, due to the important role of teamwork in palliative care.

Health care systems may also contribute towards difficult patients with productivity pressures, changes in health care financing, fragmentation of visits, and the availability of outside information sources that challenge the physician's authority. These are factors that are beyond physician control, but can contribute towards feelings of frustration, because they are obliged to comply with measures that contribute towards an unsatisfied patient, who may consequently become 'difficult' (Haas, et al., 2005).

Thus, it would seem that the literature has covered a variety of factors contributing towards a difficult patient both in general and in end of life care.

How HCWs react towards difficult patients will affect future care. Studies have shown that when patients are accepted unconditionally, i.e. when they feel accepted as they are without judgement, they will adopt less defensive and aggressive attitudes (Rogers, 1951) and Youngson (2011) argued that a change in the HCW's personal attitude can have an immediate effect on 'difficult patients', especially in relation to their ability to empathise which is an important issue and will be elaborated on here..

There is a need to distinguish between sympathy and empathy. Empathy is a 'continuing process whereby the counsellor lays aside her own way of experiencing and perceiving reality, preferring to sense and respond to the experiences and perceptions of her client. This sensing may be intense and enduring with the counsellor actually experiencing her client's thoughts and feelings as powerfully ***as if*** they had originated in herself' (Mearns & Thorne, 1988, p. 41). Sympathy involves feelings without cognition, where the HCW simply resonates with another's general mood (Halpern, 2007). Halpern argued that sympathy can lead HCWs to lose sight of their own emotions, and become more controlling and likely to pathologize, ignore, transfer, or discharge 'difficult' patients, resulting in more costs with personnel, legal expenses, and patient transfers.

Being empathetic requires a certain amount of training, which HCWs do not always have. Contrary to the above definition, in medicine, empathy traditionally refers to a purely cognitive understanding of patients' emotions, but with a certain 'detached concern', that has been viewed as necessary for objectivity in order to avoid burnout (Halpern, 2007). However, with this type of 'detached empathy', patients are not always likely to feel understood, increasing their anger and dissatisfaction. In this sense, rather than avoiding burnout, it is likely to increase it, because HCWs may not feel accomplished. However, for the HCWs to feel comfortable entering the patient's world and suffering, and engage in 'exquisite empathy' (Weiniger & Kearney, 2011) a sense of security is needed (Rogers, 1951; Mearns & Thorne, 1988). If HCWs are not adequately trained for this 'exquisite empathy' there may be consequences for their well-being, and the well-being of their patients. This will be further explored in the next chapter on interventions.

The concept of a difficult patient encompasses more than just the patient's personality, but also involves issues such as their medical condition, the emotional and physical state of the HCWs, the facilities of the institution and the health care system. In end of life care, the causes leading to a 'difficult' patient seem to be related to the patient's terminal condition. To cope with these issues in an effective manner, HCWs may require quality training enabling them to empathyse with the patient in a way that is beneficial to both the patient and the HCW.

Teamwork

Teamwork is considered to be an integral part of the philosophy of palliative care (Crawford & Price, 2003). In this section, different team models will be considered and the aspects that make for a successful team, the difficulties experienced within a team, and ways that teams can avoid burnout.

Multidisciplinary, Interdisciplinary and Transdisciplinary Models and their Success Factors

Within the three different models of teamwork described by Crawford and Price (2003), the multidisciplinary, the interdisciplinary and the transdisciplinary team, the model most used in palliative care is the interdisciplinary team approach. Rather than working in conjunction with each other to contribute towards the care of the patient, but acting autonomously and in isolation from each other, as in the multidisciplinary team, the members of an interdisciplinary team work in collaboration to interpret findings and develop a care plan that is best for the patient and family by contributing with their particular expertise, sharing and decisions and also by involving the patient's family. In the trans-disciplinary team, boundaries are blurred and the particular expertise of each team member is not clear to the patient and family. Crawford and Price (2003), claimed that this team model is not used in healthcare, but, Bruder (1994) argued that in some cases, for example in child care, the team members are required to share roles and cross discipline boundaries. The advantage of this transdiciplinary approach is that the expertise of team members is joined and integrated to form a more comprehensive assessment and intervention. The role differentiation between disciplines is defined by the needs of the situation rather than by discipline-specific characteristics. This teamwork usually results in a decrease in the number of professionals who interact with the patient on a daily basis.

In palliative care the interdisciplinary team approach is the most common model found. However, contrary to what Crawford and Price (2003) claim, although palliative care teams work essentially with the interdisciplinary model, at times, when needed, the trans-disciplinary model can occasionally be introduced. This can be verified by palliative care specialist training courses where each member of the team is required to study and have knowledge of the different disciplines, as suggested in an EAPC white paper (Gamondi, et al., 2013).

For the team to be successful, good coordination, collaboration and communication is essential. Meier and Beresford (2008), stress that a successful team does not happen automatically, but requires effort and work to achieve a collaborative practice, which can be characterized by aspects such as self-awareness, shared decision-making, trust, respect, accountability, mutual support, positive work environment, and attention to retention and job satisfaction.

Considering the criteria for successful multi-professional cooperation in palliative care teams, Jünger, et al. (2007) conducted semi-structured interviews with 19 members of a palliative care team one year after their opening. When asked to describe ‘cooperation’, communication featured strongly in their responses, followed by having a team philosophy, working within a good atmosphere, and having team commitment. Most respondents therefore felt that being able to communicate well with each other was important. Indicators for successful cooperation in a palliative care team, according to the sample, featured team performance, trust, having clear common goals, and autonomy. This study agrees that a common approach is essential and in addition, Meier and Beresford (2008) stress that an essential factor is having the appropriate mix of people, as all the other criteria could be compromised if this part is not done wisely.

Challenges to Teamwork

If the above criteria are systematically put into action, many difficulties in the team can be avoided, but a team will often require some years of working together towards these goals to become successful (Meier & Beresford, 2008), as some of these difficulties can be quite challenging.

Studies looking at the causes of stress in palliative care teams have often highlighted conflicts within the team as one of the highest identified causes of burnout, independent of their methodology. Di Tullio & MacDonald, (1999) and Pereira (2011) used semi-structured interviews with 38 and 18 HCWs respectively, both within the context of grounded theory. The strength of these qualitative methods is that the information is obtained inductively by the HCWs, analysed within a constant comparative framework, and creates the opportunity for new ideas and theories of burnout to emerge. Pereira showed that ‘difficult relationships’ was mentioned the most as a risk factor by community teams. This was described as the existence of problems, difficulties, tensions, conflicts, arguments, confrontations, opposing ideas or positions and power struggles, leading to a loss of team spirit and belonging to the team. Other studies have found similar results (De Dreu & Weingart, 2003) (Crawford & Price, 2003) (Blomberg & Sahlberg-Blom, 2007). Di Tullio & MacDonald (1999) showed that communication issues can also lead to conflicts. In response to the question ‘what is stressful about hospice work?’ 55.3% of participants referred to inadequate communication as a source of stress, especially between senior management and front-line hospice workers. Lack of support and appreciation by management and co-workers was mentioned as a source of stress by 31.6%, workplace politics was cited by 28.9% of participants and 18.4% cited ‘controlling’ co-workers.

Similar results were also found in HCWs working in oncology services with no palliative care. Florio et al (1998) performed a study with 59 oncology nurses using structured conceptualization/concept mapping (Trochim, 1995) where nurses were asked to generate statements to describe stressors and coping responses. Results showed 9 clusters, one of which was co-worker stress, which consisted of interpersonal conflicts between nursing staff and between health care aides and nursing staff. A large scale Italian study in 10 haemato-oncology units also showed conflicts to be a source of stress (Bressi, et al., 2008): negative relationship with superiors was cited by 42.15% of physicians and 36.24% of nurses and negative relationship with colleagues by 35.54% of physicians and 43.67% of nurses. Although this study by Florio et al. was not performed with such a large number of participants as the study by Bressi et al., the distribution was randomized and the methodology used a free response technique so that the participants were less likely to be biased in any way in the answers they gave. The study by Bressi et al. had the disadvantage of presenting the HCWs with a pre-prepared list of stressors for them to rate, thereby eliminating the possibility of suggesting new stressors, but the strength of the study was the high number of participants (n= 387) which made it possible to obtain significant results.

Florio et al. (1998) also identified other stressors for oncology nurses linked to physicians' attitudes, such as those who appear to abandon patients who are not doing well and those ordering futile aggressive treatments which could cause discomfort to the patient. This was supported by Fillion et al. (2003), who interviewed 110 palliative care nurses in Canada where respondents expressed their difficulty in watching patients within the hospital receiving resuscitation and invasive management on their death bed, resulting in transfer to the intensive care unit. They expressed their frustration about the lack of collaboration on behalf of doctors, who often were unavailable for prescribing adequate end of life care or undertaking home visits. This was felt to be very stressful for nurses caring for patients in pain, especially as part of their role is to advocate for the patient's well-being, and therefore, witnessing this invasive and inappropriate treatment by doctors may cause tension in the relationship.

Lack of appreciation and recognition on behalf of superiors may also be a cause of stress to nursing staff (Fawzy, et al., 1991; DiTullio & MacDonald, 1999; Fillion & Saint-Laurent, 2003), but professionals in a superior position are also subject to stress. Vachon, (2000) undertook a study with physicians and matrons which mentioned a cause for burnout that has rarely been mentioned in the literature: feelings of isolation in senior positions. Although HCWs in senior positions are part of a team, they may be reluctant to share their vulnerabilities with other members of the team because they may feel this would undermine their capacity to play a supporting role within their team. Unpopular measures may also need to be taken, the reasons for which they cannot share with other members of the team for professional reasons, and this may interfere with relationships, as discussed above.

Finally, palliative sedation (Committee on National guideline for Palliative Sedation, 2009, p. 18) has also been mentioned as a cause for stress in HCWs individually and as a team. Morita et al (2004) investigated the negative effects of palliative sedation on HCWs in a nationwide study in Japan (n=3187) with oncology nurses, with a response rate of 82%. The methodology used was a cross-sectional questionnaire survey where 82% of the nurses (n=2607) had clinical experience in continuous-deep sedation. Results showed that the lack of teamwork, common underlying philosophy and emotional support was evident in this study as contributing towards a sense of burden in HCWs, resulting in 30% of participants reporting a desire to leave their job. Similar results were found in Portugal, where palliative sedation was also mentioned as a risk factor for burnout by team coordinators (Pereira, 2011).

Challenges to Team Welfare

Junger et al. (2007) suggested that high emotional burden may become a difficulty for the team. As discussed previously, caring for patients with a terminal condition means coping with constant intense emotions, such as supporting the patient and family with their suffering and losses, as well as dealing with their own feelings of loss and sense of powerlessness. HCWs will need some form of emotional support and a united team, which is not always available (Bernard & Creux, 2003) .

When harmony and good relationships are not present, it may also be difficult for team members to share their vulnerabilities, as will be shown in this present study, increasing their sense of emotional loneliness. This again supports the need for emotional support within a therapeutic environment (Bernard & Creux, 2003).

In Portugal, a study using semi-structured interviews with 11 nurses working in palliative care showed that HCWs receive no support from the institution and participants stressed the need for a psychologist for the team to give them the support they needed (Batista, 2011). This study was carried out with a limited number of participants and this can raise questions regarding the transferability of the results to other settings. However similar results were found in a larger and more in-depth Portuguese study (Pereira, 2011) using grounded theory research where semi-structured interviews were carried out with a doctor and nurse from each team (n= 92 doctors and nurses).

It would seem that these difficulties also extend to doctors. Qualitative research by Williams et al. (2005) in the USA, using narrative analysis of student papers to identify patterns, core constructs and themes related to student's projected feelings on patient death, highlighted the difficulty 162 medical students felt when faced with a patient's death. Similar to previously mentioned studies in this section, (Payne, 1998; Friedrichsen & Milberg, 2006; Kearney, et al., 2009) these were feelings of guilt and helplessness when a cure is no longer possible, reflecting on their own personal experience of death and spirituality and also how to face the suffering of the family. This study also stressed the need for support groups to help them deal with these issues. However these papers were not originally intended for research, and only reflect the thoughts of students who volunteered their papers. The study cannot be generalized to all preclinical medical students in the USA.

2.3.3 INSTITUTIONAL FACTORS

The previous section showed professional issues concerning difficulties in communication with patients without losing one's congruency, overcoming the obstacles of teamwork and the need for emotional support was also stressed. However, institutional factors such as excessive workload and disorganisation, implementing palliative care as a new speciality and financial difficulties also play an important role in staff burnout.

Excessive Workload, Bureaucracy and Disorganization

Although it has been suggested that difficult interpersonal relationships may be related to burnout, there is research showing that excessive workload may be a major cause for stress. (Fawzy, et al., 1991; Whippen & Canellos, 1991; Ramirez, et al., 1995; Vachon, 2000; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008; Kearney, et al., 2009; Pereira, 2011). However, it appears that the reasons for excess workload have changed. In the early days, palliative care was provided in doctors' own time, and without financial compensation, which put a strain on their family lives (Vachon, 2011). Now that palliative care is accepted within the health services, the excess work may be caused by lack of staff, often due to financial constraints, and the excessive bureaucracy partly to justify all expenses (Fillion & Saint-Laurent, 2003; Pereira, 2011). Overtime may be undertaken, sometimes without pay, (Pereira, 2011) and insufficient personal and/or vacation time may become a frequent reason chosen to explain the existence of burnout. A large quantitative study with 598 randomly chosen American oncologists (Whippen & Canellos, 1991) were asked to rate a 12 item questionnaire with a list of causes for burnout and the results showed that a heavy workload and excessive bureaucracy associated with little vacation time caused a strain on physicians. Although this study did not allow new information to emerge, the design did allow a more objective approach due to the random selection of participants. Other qualitative studies also showed bureaucracy as a strong cause for burnout (DiTullio & MacDonald, 1999; Vachon, 2000; Fillion & Saint-Laurent, 2003; Pereira, 2011). Inadequate pay was mentioned by two studies from the USA (Florio, et al., 1998; DiTullio & MacDonald, 1999) and one Italian study (Bressi, et al., 2008).

In Portugal, where palliative care has developed relatively recently, lack of beds and disorganization is also mentioned as a source of stress for the nurses (Pereira, 2011) and in Italy, where the hospice movement started in the early 1980's (Toscani, 2002) and where the first hospices emerged in 1999 (Zucco, 2010), disorganization was also considered a risk factor (Quattrin, et al., 2006). This large Italian study with 100 nurses working in oncology showed high levels of emotional exhaustion in the subjects who attributed disorganization as an important cause of stress, whereas, in the nurses who did not, levels of emotional exhaustion were considered moderate. Levels of depersonalization in the subjects who attributed disorganization as an important cause of stress was considered to be moderate, and in the nurses who did not, levels were low. The study therefore confirmed that disorganization caused the highest level of emotional exhaustion. However disorganization only had a moderate effect on depersonalization. This would suggest that HCWs were able to maintain a good relationship with patients despite difficult relationships with colleagues.

These stressors may also be present in countries where palliative care is more established, such as Canada where the lack of links and coordination within establishments may also lead to disorganization and an increased risk of burnout for staff. For instance, as patients are often cared for by different units, according to the state of disease, they are constantly in and out of ambulatory or emergency units, and when they come to the point where there is no cure, they may find themselves 'stranded' without a department or doctor who follows all their care (Fillion & Saint-Laurent, 2003). The studies in this section suggest that adequate organisation and careful planning are essential in the development of services and thus may be also be essential in reducing burnout for the HCWs involved.

Challenges to Palliative Care as a New Specialty

Junger et.al. (2007), suggested that there are particular difficulties in palliative care, where there may be less well defined standards compared to other medical fields because it is a relatively new specialty. This is also the case in Portugal, where the first palliative care team emerged in 1996 (Lourenço Marques, et al., 2009). When setting up new units, HCWs are confronted with various difficulties such as lack of recognition on behalf of politicians as to what palliative care actually is (APEME, 2008; Lynch, et al., 2010), cumbersome bureaucratic pathways that delay the acquisition of all the necessary medication a palliative care unit needs as well as the admission time of patients, a lack of qualified personnel, and lack of funding, thereby hindering their smooth functioning. (Unidade de Missão para os Cuidados Continuados Integrados, 2010). In this sense, the actual health care system for end of life care can be a source of stress for HCWs.

For HCWs who work in palliative care, their role may not be well understood and appreciated, which can be frustrating. They may be seen by the public and many other HCWs as a place people get sent to die, rather than as a service that can help them live well until death. A Portuguese public survey revealed that only approximately half of the public thought palliative care was only 'care that gives dignity to dying people' (APEME, 2008) and there was a lack of understanding of the aims and role of palliative care. This may lead to a strain on HCWs as they try to provide holistic care, within a heath care system that neither understands their needs nor provides adequate support and staffing to undertake the complex roles.

This lack of recognition of the role of palliative care was described by Ruszniewski and Zivkovic (1999) who suggested several contradictory difficulties in the collaboration between teams. Whereas some less medically and emotionally equipped units may want to completely hand over the terminal patient to the palliative care team, others may be reluctant to collaborate as it may reveal deficits in knowledge, or may be due to emotional attachment to the patient. For the palliative care HCWs it may lead to feelings of frustration at not being able to provide the same quality of care to the patient and family as would be possible if there were full collaboration between teams and it also presents a challenge for them to find constructive ways of dealing with attending teams in a diplomatic way, that will on the one hand empower them to take part in palliative care and on the other hand help them accept help without feeling threatened (Ruszniewski & Zivkovic, 1999).

Added to this, Vachon (2000) referred to lack of training in physicians as a challenge to palliative care units. She found that 35% of the physicians felt insufficiently trained in communication and 81% in management skills. Nurses also expressed fears regarding their ability to perform their job due to inadequate training (Florio, et al., 1998). In Portugal, this lack of awareness also has an impact on formal palliative care training. The number of people receiving palliative care education is insufficient, resulting in a scarcity of trained personnel, and a lack of doctors with formal training, to open palliative care units (Neto, 2010; Jornal de Notícias, 2012). Moreover, many doctors are still fearful of using opioids adequately, resulting in poor pain control, and the role of palliative care is not completely understood because it is often reduced to simple physical pain control, rather than taking into consideration the concept of total pain (Lynch, et al., 2010).

As a result of this, HCWs who do have training become acutely aware of the standard of care that should be available for all patients with a terminal condition yet are unable to ensure high standards because they are a minority within the team. This problem also exists between nurses with specialist palliative care training and physicians who are not trained in palliative care which can make team work more difficult and frustrating. (Fillion & Saint-Laurent, 2003). Likewise, HCWs who care for patients with a terminal condition without formal training may experience feelings of helplessness and not being in control of the situation, which can decrease their level of professional satisfaction and lead to burnout as shown in previously mentioned models of burnout (Leiter & Maslach, 2005).

Difficulties Arising From Lack of Funding

Limited funding of services can also be an issue (Lynch, et al., 2010). Portugal has both state funded, private or semi-private palliative care units. With the present economic situation, there is pressure to reduce costs and this can cause difficulties for the HCWs, who have an ethical obligation to put patient care first, but who, as already mentioned, will also be pressed by the hospital administration to justify their spending and to cut costs, or simply not have the budget to give optimal care. (Pereira, 2011). The cuts in costs in Portugal will affect the availability of medication, the number of employees and paid overtime (Diário de Notícias, 2011).

Lack of funding for the provision of psychological support for palliative care teams has also been shown to be a source of stress (Fillion & Saint-Laurent, 2003).

2.3.4 INSTITUTIONAL CONSEQUENCES OF BURNOUT

The following section will address possible causes for reduced quality of patient care and efficiency, and how this impacts on the institution. The aim is to show that it is important to address these issues, not only for the well-being of the HCWs, but also for the benefit of the institution.

Reduced Quality of Patient Care

There are many consequences of burnout – on the person themselves and their patients and families for whom they care but also for the institution and the wider community.

Bernard & Creux (2003) in a study looking at the psychological effects on nurses, of caring for dying patients, suggested that HCWs can set up defence mechanisms to protect themselves, such as lying to the patient about their illness, trivialization or derision, which can have a very negative effect on the patient, who will no longer feel at ease to talk about their troubles. This ends in the patient feeling isolated in his world of illness. For the HCWs there may be feelings of anger against themselves, or deep dissatisfaction for not having been there for the patient when needed. Bernard & Creux (2003) also suggest that nurses should be encouraged to participate in discussion groups, because these difficult situations can affect them both physically and emotionally, increasing the risk of burnout. However, an Israeli research by Shirom et al. (2006) with 890 physicians from different specialities carried out studies on the relationship between objective workload, overload (perceived workload), autonomy, burnout and perceived quality of care. Results showed surprisingly that global burnout did not significantly predict quality of care. Emotional exhaustion was significantly negatively correlated with quality of care, but physical fatigue was significantly positively correlated. The explanation given for this, was that HCWs may either try to compensate their tiredness by trying not to let this affect their patients, or because they attribute their feelings of physical exhaustion to the provision of higher quality care. However, this study was not carried out with physicians working in end of life care and measurements of quality of care were perceived and not objective. Several other studies have found that not being able to find quality time to be with the patient was a consequence of excess work and this in itself is also a source of stress and dissatisfaction at work (Whippen & Canellos, 1991; Fillion & Saint-Laurent, 2003; Pereira, 2011).

There seems to be some controversy over what leads to emotional exhaustion and reduced quality of care. Where some studies seem to show that work overload affects quality of care due to the lack of time available to spend with the patient, (and not because of the HCWs' attitudes) and this in turn can lead to stress and reduced satisfaction at work, eventually leading to emotional exhaustion (Whippen & Canellos, 1991; Fillion & Saint-Laurent, 2003; Pereira, 2011), others suggest that defense mechanism are responsible for reduced quality of care towards patients, eventually leading to emotional exhaustion (Bernard & Creux, 2003).

Lack of awareness of the role of palliative care and the cumbersome bureaucratic pathway has consequences for patients and families, for although there have been great improvements in the provision of palliative care, it is still difficult to obtain palliative care for all patients in need (RNCCI-Rede Nacional de Cuidados Continuados Integrados, 2011). The total number of palliative care units in the country accredited by the Portuguese Association for Palliative Care is 22 for a population of 10 million people. (Associação Portuguesa de Cuidados Paliativos, accessed on 22.8.2012) Moreover, some of these units are privately funded and inaccessible to the average patient. In comparison, the number of services in the UK in 2007 was 882 (population of 65 million) and in Spain, 262 (population of 47 million) (Centeno, et al., 2007).

For this reason, it has been suggested that dying without dignity occurs often in Portugal (DECO, 2011) and many patients with a terminal condition are cared for at home by the family without access to adequate home care. When a crisis emerges, they are taken to the emergency room, where they can be admitted to die, or sent back home again, until the next crisis. A patient who needs to be admitted to a palliative care unit or receive palliative care at home often dies before receiving the care because there is a long waiting list, (DECO-Defesa do Consumidor, 2011; Reis, 2011) and a complicated bureaucratic pathway (the National Network for Integrated Continuing Care) that may delay the process and may be unfamiliar to HCWs.

Reduced Efficiency for the Institution

Vachon (2000) described the many symptoms of burnout which include physical and emotional exhaustion, gastro-intestinal disturbances, sleeplessness, depression, frustration, low morale, increased job turnover and impaired job performance. All of these symptoms can contribute towards reduced efficiency, but job turnover and impaired job performance are specific consequences for the institution. Several other studies have confirmed these findings. Borritz et al (2006) undertook a study with 824 participants from different human service sector organisations in Denmark with the aim of investigating whether burnout predicted sickness absence in human service workers. The findings indicated that burnout does predict sickness absence and that therefore, reducing burnout is likely to reduce this. Ahola et al. (2008)

undertook a study with 3151 Finnish employees and showed that severe burnout is associated with a substantial excess risk of medically certified sickness absence among both men and women. This association was independent of prevalent mental disorders and physical illnesses. However, both these studies were not performed exclusively on HCWs who cared for patients with a terminal condition.

Research to study the relationship between sick leave and burnout specifically on HCWs who care for patients with a terminal condition have not been found. However, in 2009, Leiter & Maslach (2009) undertook a study regarding nurse turnover and burnout with 667 Canadian nurses. Data on areas of work life, burnout, and turnover intentions were collected and the findings showed that cynicism was the key burnout dimension for job turnover. Their results showed that workload had a direct link to exhaustion, that exhaustion predicted cynicism, which predicted inefficacy. The primary issues for cynicism were found to be exhaustion as as function of unmanageable workload, value conflicts and unfairness in settings that do not support a nursing model of care and inadequate reward systems.

These studies show that the institution and the health care system can contribute significantly towards burnout in HCWs through work overload, excessive bureaucracy, disorganization, financial restrictions and an overall lack of awareness of the importance of palliative care, and this also has significant consequences for the patient and ultimately for the efficiency of the institution itself.

2.3.5 SECTION SUMMARY

This section addressed personal, professional and institutional causes and consequences of burnout, which are summarised in the following diagram (fig.3):

Personal related difficulties covered issues such as death anxiety/existential issues, death anxiety/reminder of vulnerability and mortality, unresolved grief or projected losses, helplessness and the limitations of medicine. Professonal/Communication related difficulties covered issues such as difficult patients and families, and avoidance behaviours. Professional/ team related difficulties covered issues such as lack of care for the team and conflicts. Insitutional related difficulties covered issues such as lack of personnel and working overtime, lack of funding, lack of interdisciplinary cooperation, increased bureaucracy, lack of drugs for adequate pain control, lack of awareness of what palliative care is and increased disorganisation. Further details of each category are listed in the diagram.

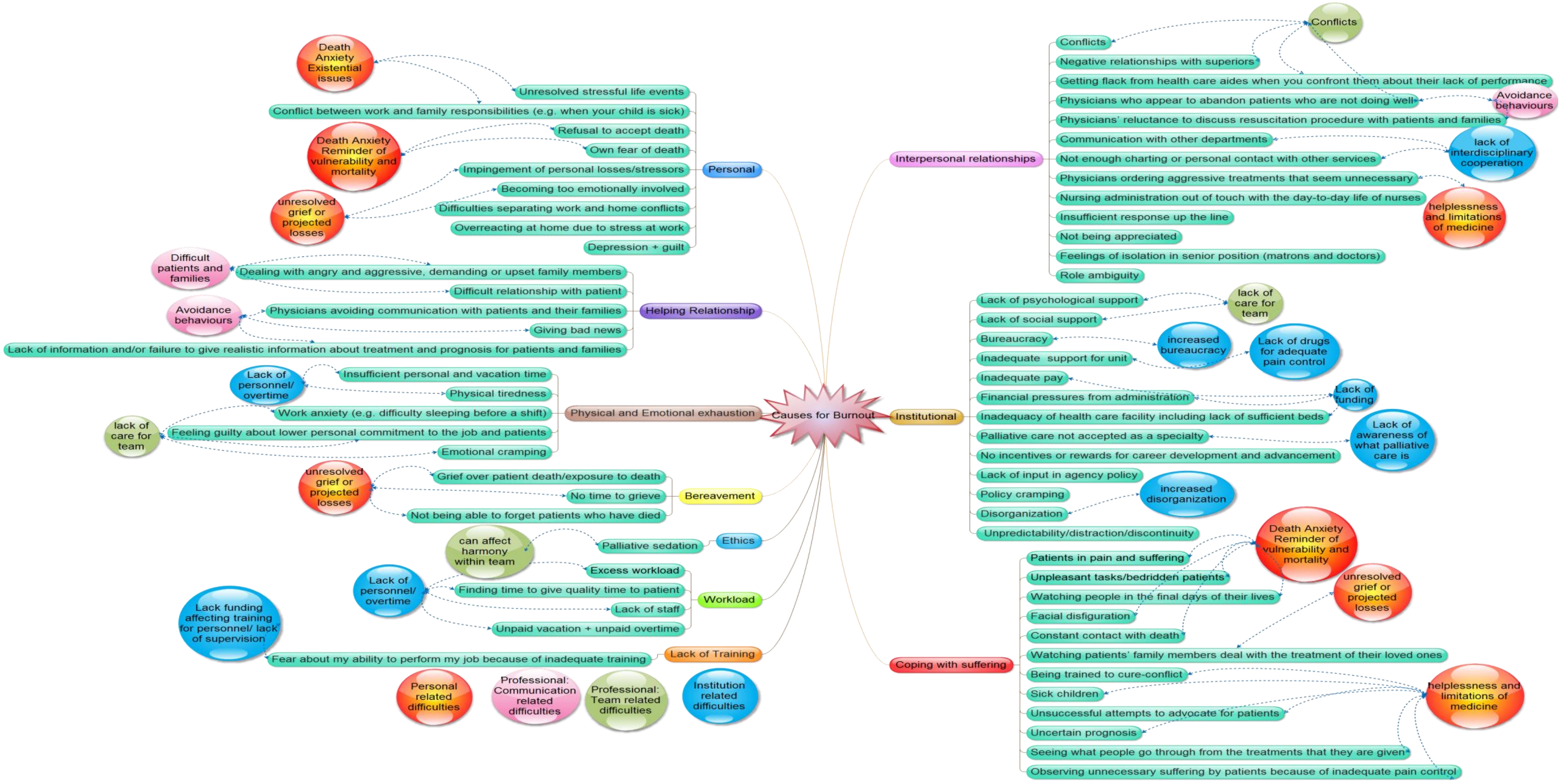


FIGURE 3 - CAUSES OF BURNOUT IN END OF LIFE CARE

This chapter has highlighted the different frameworks of burnout, followed by an analysis of factors that lead to burnout in HCWs who care for patients with a terminal condition. The following section will bring to evidence how end of life care has other specific factors that contribute towards burnout that have not been contemplated in previous frameworks and will suggest a new framework for burnout specific for this sector of HCWs.

2.4 THE NEED FOR A NEW PERSPECTIVE OF BURNOUT FOR HCWS IN END OF LIFE CARE

Several studies have shown that burnout is comprised of an imbalance between exhaustion, cynicism and job demands on the one hand, and feelings of efficacy and having adequate job resources on the other (Karasek, 1979; Demerouti, et al., 2001; Leiter & Maslach, 2005). The model suggested by Demerouti et.al (2000), included diminished life satisfaction as a result of burnout, but no other models of burnout were found for HCWs who care for patients with a terminal condition, that included the dimension of personal well-being in their models as a variable that can contribute towards the prevention of burnout. However, the causes for burnout mentioned in the literature review for these HCWs also include those related to death anxiety, as shown in fig. 5 and this may affect personal well-being:

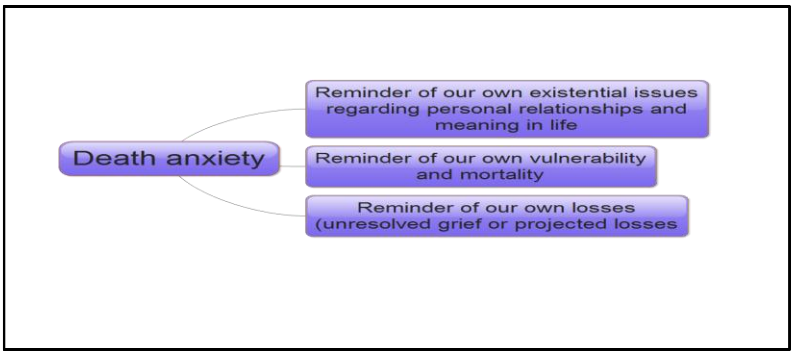


FIGURE 4 - DEATH ANXIETY CONTRIBUTES TOWARDS BURNOUT

These are personal issues that can be a source of stress, anxiety and exhaustion for HCWs who are constantly faced with these issues in the patients they care for. If the HCW is insecure and incongruent facing these issues, this may have an effect on work efficiency and on the relationship with patients.

Therefore it may be suggested that a framework to reduce burnout for HCWs who care for patients with a terminal condition could be developped from the mediation model of burnout by Leiter & Maslach (2005), because it is a model that brought together some of the concepts from previously tested models of burnout, as shown in fig. 2 and has been tested on HCWs and in particular on nurses (Leiter & Maslach, 2009) and from other models that take into consideration existential well-being, personal coping mechanisms and life satisfaction (Pines & Aronson, 1988, Fawzy, et al., 1991, Demerouti, et al., 2000). However, in view of the findings highlighted in the literature review and summarised in fig. 3, it can be argued that this framework should also include a dimension that helps these HCWs increase their internal congruence towards death and suffering and their coping mechanisms. This may be achieved through personal development and practical training, that could help them to increase their confidence and capacity to cope with these issues, enabling them to integrate within their way of being, the attitudes necessary to provide “an exquisite quality of presence” (Kearney, et al., 2009, p. 1160) to the dying without losing their internal congruence. This dimension of internal congruence should consist of:

- Personal development to reflect upon the time and quality of relationships that HCW’s have with their loved ones and whether they feel their own life has meaning, on becoming aware of their resources and coping mechanisms to deal with challenges and the unknown and to enable them to cope with illness, suffering and the death of their patients as well as the prospect of their own aging, loss of dependency and death;

  and:

- Practical training that will provide knowledge on how to provide an ‘exquisite’ quality of presence for patients, by increasing their capacity to empathize and to accept others in a non-judgmental way and by encouraging them to incorporate these attitudes in their way of being as suggested by Carl Rogers (Rogers, 1980). The term ‘exquisite’ has been adapted from the concept of ‘exquisite empathy’ (Weiniger & Kearney, 2011). (See section 2.3.2 - ‘Dealing with the difficult patient’). This should be accompanied by continuous supervision.

This may in turn improve their sense of self efficacy and control, and also have the effect of improving their working conditions as a team encouraging them to collaborate with each other towards a common goal.

This section has aimed to show the need for a new framework to cope with burnout in end of life care. This can be seen in fig. 5, which shows the same model as fig 2, with all the different models of burnout culminating into the mediation model of job burnout (Leiter & Maslach, 2005) (in grey) and adds two sections (in colour). These summarise the causes for burnout in end of life care and address its prevention, based on the need for personal development to increase personal well-being/congruence and initial training + continuous supervision to increase control and integrate knowledge within self. Areas related to death anxiety have been shown in orange.

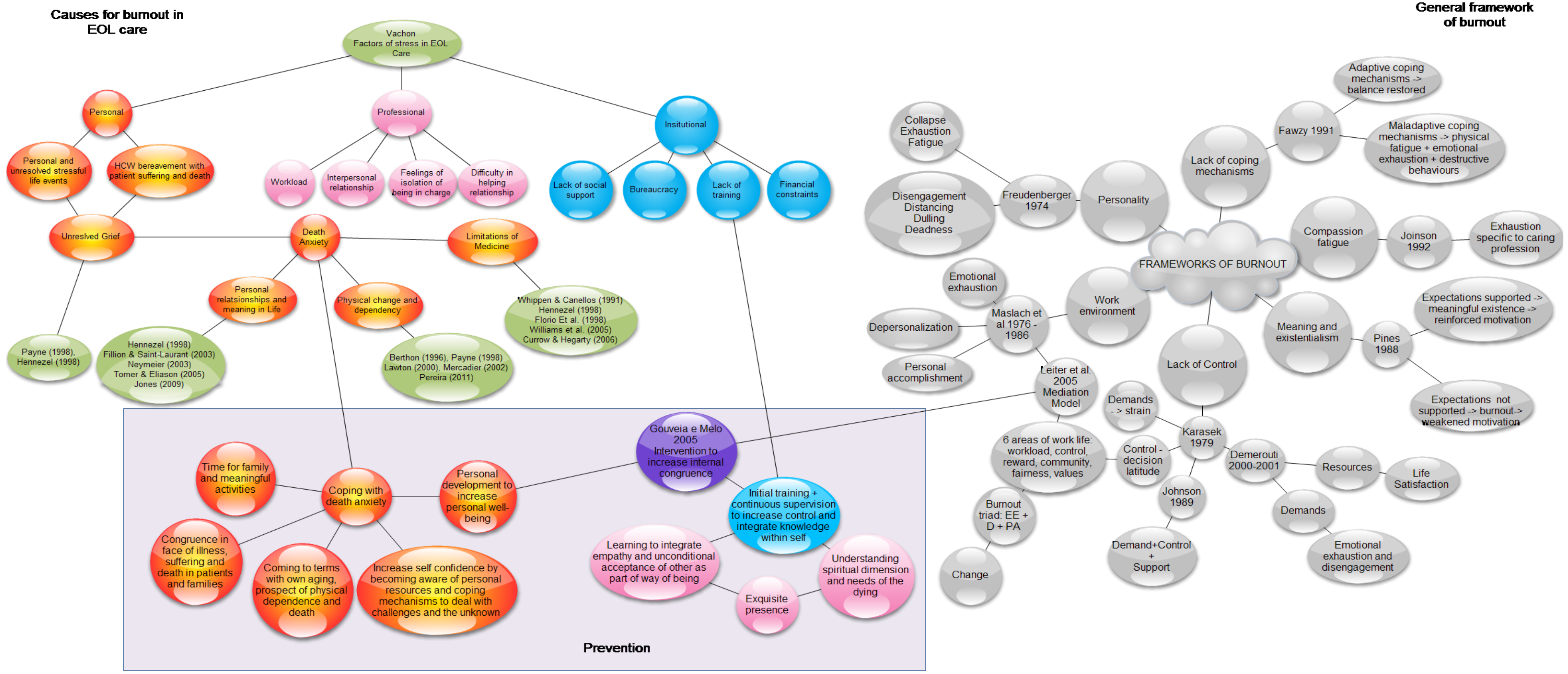


FIGURE 5 - SUMMARY OF THE LITERATURE REVIEW ON FRAMEWORKS FOR GENERAL BURNOUT AND BURNOUT IN EOL CARE, INCLUDING PREVENTION

2.5 INTERVENTIONS TO PREVENT AND REDUCE BURNOUT IN END OF LIFE CARE

The previous section on burnout highlighted the need for a framework of burnout in HCWs who care for the dying that also includes a dimension of internal congruence by addressing death anxiety and providing training that will help them provide an ‘exquisite’ quality of presence for dying patients. This section starts with a brief history of interventions to help HCWs cope with death and dying followed by an analysis of the content, teaching methods and format of such interventions, with the aim to understand what is most appropriate and effective.

2.5.1 AN INTRODUCTION ON THE BEGINNING OF TRAINING INTERVENTIONS TO HELP HCWS COPE WITH DEATH AND DYING

Interventions focusing on the well-being of HCWs in end of life care have mostly been developed in the USA, Canada, UK and France where palliative care first developed.

Kübler-Ross (1970) depicted the difficulty HCWs in the USA experienced with the issue of death and dying and how this could affect their capacity to support their patients. Wass (2004) showed that in the USA, personal development to cope with this difficulty started to be included more systematically in courses in the 1990’s.

Dame Cecily Saunders began the modern hospice movement in the 1960’s in the UK with a different approach from the USA, based on scientific evidence. Research on the provision of effective pain and symptom control was performed and the need for emotional and spiritual support to complement pain control became evident resulting in the concept of total pain. Emotional support for HCWs seems to have also developed at a later stage. Blanche (1997) describes a staff support course at the Princess Alice Hospice which was multidisciplinary, with a maximum of 9 – 12 members per course to allow for greater introspection. The course followed three principles: enabling and empowering staff to look at their own situation and recognize their own ability to deal with stress and grief; embracing a multidisciplinary approach including all the departments in the hospice and finally, the inclusion of an element of teambuilding and the recognition of everyone’s part in providing effective patient care. This course was well appreciated by those involved. They felt more confident, understood their own stress and those of other team members, understood grief better and became more aware of their need for support. Being part of a group and understanding that problems and concerns were similar for all members was found to be beneficial (Blanche, 1997). It would seem that the strength of this intervention was the small number of participants, allowing for greater attention to each participant and the fact that it was interdisciplinary, which could improve team collaboration. However, it was only 2 ½ days, stretched out over a long period of time, which may have been insufficient time for consolidated personal growth.

Palliative Care developed relatively quickly in France due to their close relationship with Canada where training for doctors was well established, the extensive government work, publications (Laroque, 1986) and the work of Marie de Hennezel (Hennezel, 2012). In 2002 the French government issued a document defining the functioning of palliative care in France which took into consideration the welfare of HCWs. This included three types of training and support for

HCWs: multidisciplinary training to learn how to work within a network, palliative care training with clinical case studies and support of the HCWs. (Direction Générale de la Santé, 2002).

Pronost and Tap (1997) studied the benefits of training to increase coping mechanisms and prevent burnout on 187 nurses working in end of life care in France and they also took into account the emotional aspects of HCWs. This showed that those with training in palliative care used more positive coping mechanisms, such as social support and control whereas those without training used more negative coping mechanisms such as withdrawal, denial and defensive attitudes. It also showed that those with more training had higher levels of personal accomplishment. This study used the MBI, which does not contain items specific for end of life care. Had burnout been measured specifically for end of life care, levels of burnout may have been higher. However the results still showed significant differences between the two groups, which highlights the importance of training.

2.5.2 THE NEED FOR INTERVENTIONS WITH SELF DEVELOPMENT THAT ADDRESS DEATH ANXIETY

As shown previously, death anxiety can contribute towards burnout. The following section brings forward some studies that have analyzed the need for interventions to cope with death anxiety and the relationship between death anxiety and attitudes towards patients. Issues that lead to death anxiety, as discussed in the previous section on burnout do not seem to be approached in the education of student nurses and doctors.

Williams, et al. (2005) showed that 108 first year medical students in the USA overwhelmingly identified the need for coping strategies when confronting patients with a terminal condition, and added that an end of life curriculum is more than just teaching about the clinical care of the patient and support of family.

Similar findings have been made with trained doctors. Neimeyer et al. (2004) performed an overview of the literature and found that death anxiety in doctors can increase reluctance to inform patients of their impending death, and also to increase the tendency to perform heroic treatments to prolong their lives. They suggested that death attitudes and consequently professional responsiveness might be improved through specialized training.

Similar results were seen in studies with nurses. Ezquerro, Román, & Sorribes (2001) evaluated death anxiety using free-association studies, where nurses were asked to think of a terminally ill patient and answer each item of a questionnaire, with words that they associated or related to each of the items. Results showed a slightly negative trend in attitudes towards the terminally ill, but lesser so in older caregivers and women. This situation in Spain has been confirmed more recently in a study with 146 nursing students which showed a high percentage of nursing students with moderate to high levels of death anxiety which can affect patient care. (Limonero, et al., 2010). It would seem therefore that research shows that death anxiety in nurses does affect patient care, especially in less experienced nurses. This is consistent with studies mentioned previously, that show that younger nurses are more prone to burnout (Maslach, et al., 2001), (Vachon, 1997), but not with others that show the contrary (Quattrin, et al., 2006) (Lissandre, et al., 2008). However, burnout in older HCWs may occur for different reasons as previously discussed.

These studies seem to show the need to address death anxiety in order to achieve competent empathic responses towards clients and avoid distress levels in HCWs.

The gap in this area of education continues to be the case as shown by Dickenson (2007) who carried out a study with 122 medical schools and 580 nursing programs in the United States to find out how much preparation is given to end of life (EOL) care. This showed an average of less than 15 hours during the entire curriculum and his studies also showed that existing EOL issues are not presented in an in-depth way. They argue that students cannot really be trained to work with patients with a terminal condition before they feel comfortable with the topic, and that they need to think about their own values and beliefs about dying before they can be caring and insightful to dying persons and their families (Walton & Alvarez, 2010).

This has also been supported in Portugal, in a mixed method study where 268 nursing students responded to a questionnaire on causes of stress in nursing students and 24 participated in focus groups. Results showed that the main causes for stress were lack of competence, contact with suffering, relationship with the patient and lack of time, the relationship with teachers, supervisors and colleagues and being hurt in a relationship with a patient. The study ended with a recommendation for the development of the nursing curriculum in relation to death and dying with measures such as the creation of peer support programmes, stress management programmes, a unit for psychosocial counselling, specific training for teachers and suspervising nurses to be able to perform clinical supervision and 'Learning Diaries' for self reflection. (Barroso, 2009).

Studies have also been performed to specifically understand the needs of nurses and doctors in education. Fillion et al. (2005) undertook a survey with 197 nurses working in acute and community care in Canada, and showed that crisis, stress and emotion management were the most requested, followed by other areas such as understanding the emotional and spiritual needs of the dying person and their family and counselling skills. Hegedus (2008) carried out a study on 127 HCWs and 41 undergraduate medical students which showed that what arouses the strongest fear are existential issues such as fear for significant others, (apprehension about the impact of the respondent's death on significant others and of their deaths on the respondent), fear of the unknown (including fear of nonexistence) and fear of the dying process (painful and violent death). It would seem that this is in line with the findings of Fillion, that crisis, stress and emotion management are necessary for these HCWs. Results showed that training decreased this anxiety due to increased knowledge of high-quality care of patients with a terminal condition and the opportunity for open communication within the group regarding issues that raise anxiety.

Other studies have been undertaken to specifically understand the consequences of death anxiety in nurses. Lange et al. (2008) assessed death anxiety using the Frommelt Attitude Toward Care of the Dying (FATCOD) (Frommelt, 1991) and the Death Attitude Profile-Revised (DAP-R) (Wong, et al., 1994) questionnaires with 355 oncology nurses in a N.Y cancer centre and found that the fear and avoidance of death and dying that is present in less experienced nurses was correlated with less positive attitudes toward caring for patients with a terminal condition. However, Lange et al. claimed that although the sample was relatively large, it may not have been sufficient to generalise these results and it is also possible that the self report methods used may have resulted in falsely positive responses. The study by Braun et al. (2010) with 147 Israeli nurses exposed to death in their daily work, also using the FATCOD and the DAP-R questionnaires also confirmed that positive attitudes towards the dying were significantly negatively correlated with death avoidance, fear of death, and death avoidance played a mediating role between fear of death and attitudes toward caring for patients with a terminal condition. These results occurred even though 89% of the participants were Jewish with different beliefs of the after life. However a possible limitation reported was the response rate which was low. It was postulated that nurses with a strong fear of death or death avoidance may have avoided participating in the study. They concluded that training and support programs for oncology nurses should take into consideration nurses' personal attitudes toward death as well as their religious and cultural backgrounds.

It would seem that studies have shown how HCWs are ill prepared for coping with death and the suffering of their patients. This is an area of education that has not been well addressed and HCWs have identified the need for better personal preparation in relation to existential issues, as well as crisis, stress and emotion management. The following section critically analyses existing interventions that address these issues.

2.5.3 SELF DEVELOPMENT IN INTERVENTIONS IN END OF LIFE CARE

Interventions to help HCWs avoid or reduce burnout or cope with death and dying have focused on different areas and this section will focus on death anxiety and life satisfaction. The aim will be to show the different types of self development in interventions designed to help HCWs cope with death and dying, and their effectiveness.

Death Anxiety and Attitudes Towards Patients with a Terminal Condition

Mok et al. (2002), undertook studies in Hong Kong, China, where talking about death is often considered taboo. A problem-based learning program was given to 96 student nurses and they were able to talk about their own difficulties when caring for the dying, find meaning in death, and examine their behaviour and how they envisioned their own death. They were also required to keep a journal and cross case analysis of cases documented in their journals showed that there was an improvement in their attitudes and caring behaviours towards the dying. The results also showed that participants found these methods promoted self reflection and they found comfort in knowing that others had the same difficulties, which in turn lowered their anxiety in caring for patients with a terminal condition.

Mallory (2003) goes further and argues that in order to care for the dying, HCWs need to incorporate certain attitudes into their way of being. She studied the impact of a 6 weeks course on palliative care education (ELNEC) on attitudes towards the dying with 104 undergraduate nursing students. The course consisted of theoretical on-line learning, role play and patient interaction with experience in a hospice. The underlying theory behind this course is that exposing nurses to patients with a terminal condition without specific education on how to care for them can result in the nurses suffering from death anxiety. The teaching methodology used here was based on transformative learning theory which is gained through critical self reflection rather than just the acquisition of technical information. The transformation occurs when students incorporate what they have learnt into their belief system, thereby changing who they are. The intervention was evaluated using the FATCOD questionnaire (Frommelt, 1991) and the results showed positive changes with improved attitudes towards death and dying. This intervention offers an additional component from the previously described intervention as it shows the success of self development associated with a practical component as well.

Wessel & Rutledge (2005) also studied the relationship between attitudes towards the dying and death anxiety through a 6 month intervention which included theoretical information, educational videos, clinical practice and narrative reflection writing, but focused mainly on the patient, with issues such as goals of end of life care, care in the final stage of life, pain and symptom control, ethics, communication techniques, and spirituality. There was no component of self development. The study was carried out with 33 home care and hospice nurses. Results showed that some attitudes toward death improved but there was no significant change in attitudes towards care for the dying. Only an overall slightly positive trend was noted. This lack of significant change could be due to the lack of self-development in the course. However, the nurses that took part in the intervention were home care nurses who were already providing a high quality level of care, and it is possible that there was perhaps little room for significant improvement.

It would seem that these studies highlight the need for self development to cope with death anxiety and to improve the quality of patient care. Similar effects have been found in interventions focusing on life satisfaction as shown in the following section.

Self Care and Life Satisfaction

Rather than focusing directly on death anxiety, other studies have focused directly on the well-being of the HCW. Mackenzie, et al. (2006), evaluated burnout in relation to relaxation, and life and job satisfaction through a four week mindfulness-based stress reduction intervention with 16 nurses working in continuing care. The course consisted of exercises such as mindfulness eating, stretching, breathing and awareness of thoughts and paying attention to practice barriers and to their likes and dislikes. A control group of 14 nurses was used. Although changes did occur in all areas, the most significant changes were in emotional exhaustion, relaxation and life satisfaction. No significant changes were reported in the control group.

These results are interesting, because the course was not directly based on existential issues, life events and death and dying, but concentrated on the awareness of living in the moment (eg. ‘In most ways my life is close to my ideal’, ‘The conditions of my life are excellent’ and ‘If I could live my life over, I would change almost nothing’). However, in spite of this, it seemed that this training did improve their existential well-being and allowed them to live with more satisfaction in the present and with more acceptance of the past. It did not however, evaluate attitudes towards patients with a terminal condition and no evaluation was carried out in the months following the program’s completion.

Teaching Methods and Techniques

An analysis of different studies has shown that teaching methods which use a combination of different techniques are more effective.

Delvaux et al (2004) provided a 105 hour course in psychological training with 115 oncology nurses, which included theoretical information, and behavioural techniques such as role-playing and experiential exchanges. It consisted of basic communication components in oncology, psychosocial dimensions associated with cancer and its treatment, coping with patients' uncertainties and distress, detecting psychopathologic reactions to diagnosis and prognosis, and discussing death and euthanasia. Results confirmed the training impact on professional stress and attitudes. HCWs felt more competent caring for the dying and this in turn reduced their levels of stress. These results were maintained after a period of 3 months. However, more improvements were shown during the training exercises than after training, in actual patient interviews. This was explained by the heterogeneity of actual patient interviews that did not facilitate changes to be observed and also, by the lack of support within the team, professional conflicts and heavy workload which may have reduced HCWs motivation to use their skills in the clinical setting. However, in spite of this, patients that interacted with trained HCWs reported higher satisfaction with some dimensions of their communication skills.

Other studies have also suggested that a variety of teaching methods show better results. Luquette suggests that combinations of interventions appear to be more effective than any single intervention and that nurses usually learn self-care strategies through personal experience or the advice of colleagues (Luquette, 2007).

This was illustrated in a spiritual training course designed by Shoemaker (Wasner, et al., 2005), which combined different techniques with self development exercises such as in-depth reflection on one's own fear of death, and learning firsthand about the needs and the hopes of the dying. It involved 63 palliative care professionals (48 of whom completed the questionnaires) with the aim of enabling them to recognize the different facets of suffering of the dying person and their relatives and to respond effectively. The participants learned techniques of active and compassionate listening, and how to recognize and address the causes of emotional and spiritual suffering. Practical exercises were presented to enable the participants to connect with disturbed or cognitively impaired patients, to learn how to deal with unfinished business and be able to support the bereaved. Furthermore, non-denominational spiritual practices such as contemplation and meditation were introduced, which could help the participants apply and experience the benefits of spiritual care for themselves, and learn how to integrate these techniques for calming the mind and deepening compassion in their professional work. The study showed strongly significant results immediately after the 3 ½ day course regarding attitudes towards the dying, fear of death and dying, work related stress, self care and life satisfaction, and team relationships. However, with the exception of self perceived compassion for the dying and oneself and attitudes towards colleagues, these results decreased over 6 months, and quality of life, finding work meaningful and fear of death actually showed no significant difference at this time. However, Yalom (1995) suggests that the ideal size of an interactional therapy group is between 7 and 12 participants and as this intervention contained 63 participants. This may have been too many participants to allow for individual attention in a period of 3½ days. Some participants had commented that regular meetings or a refresher training every 6 months would be helpful. The evaluation of the study was only quantitative which limited the results and a qualitative approach may have been more appropriate to address the role of spirituality and religion in palliative care and how they affect burnout, the quality of life and the quality of the work of palliative care professionals.

This need for continuous supervision was also shown in a study by Hjöleifsdóttir et al. (2000) with 4th year undergraduate nursing students who were interviewed with the aim of understanding if they had concerns about communication with patients with a terminal condition and dying cancer patients and their families. Most considered that university lectures were beneficial but insufficient. There was a need for additional clinical supervision and support when they were actually having a conversation with patients with a terminal condition, because they felt it difficult to put into practice the knowledge gained in lectures. In this study most of the students had not experienced encouragement to communicate with patients with a terminal condition, or experienced their mentors speaking to them about how to communicate with these patients. However, one needs to take into account that this study was small and may not be representative of the larger student population (Chenitz & Swanson, 1986; Charmaz, 2006)

The Format of the Intervention

Successful studies have shown that the format of the intervention also plays an important role. Rushton et al. (2009) argues that there is a need for experiential and relational teaching formats and greater attention to cultivating self awareness when designing courses in palliative care.

The Need for Group Interventions with Personal Development and Face to Face Discussions

Salmela-Aro, et al. (2004) carried out a study with a group of 62 participants suffering from severe burnout, who participated in 16 sessions of either analytic or experiential group psychotherapy over a period of one year. The control group consisted of 28 participants. Although this study did not involve HCWs, the results did show that group interventions in the form of group therapy can reduce levels of burnout, increase one's capacity to make use of social network, decrease negative emotions and actions towards projects and decrease the number of work related projects, thereby increasing time for personal life. These would be important results if applied to HCWs who often suffer from work overload. The content of this course included experiential group therapy, using active therapeutic interventions such as psycho and socio dramatic techniques (muscle relaxation and drama techniques) and group analytic therapy using free association.

The use of face to face discussions has also proven to be beneficial. The drawbacks of on-line courses and those that just transmit knowledge was stressed by Wass (2004) who claimed that self-directed study may be economical but it deprives the learner of the opportunity for face-to-face interactions, which are essential aspects of the learning experience and it is also more difficult to become comfortable with the subject of death, to ease anxiety and worry, and to develop empathy. She argues that they may be appropriate if the goal is just transmission of knowledge, but not for attending to the personal dimension in learning about death, dying, and bereavement. This was illustrated in an intervention reported by Kurz and Hayes (2006) where self reflection was encouraged, but in an unsupervised way, as the course was on-line and students were not interacting with each other or supported by a therapist. Results showed that immediately after the course, levels of death anxiety actually increased. This raises questions about the format of EOL courses: to what extent should one encourage self reflection without the adequate therapeutic support?

The Need to Be Part of a Safe Non-Judgemental Environment

A non judgemental environment is a requirement for creating a favourable therapeutic environment, both individually and within a group (Mearns & Thorne, 1988), as would be the case with emotional support for HCWs. It is not easy for colleagues to show their vulnerabilities to each other for fear of being judged. However if the facilitator succeeds in creating a safe environment of acceptance and confidentiality, protective barriers may come down, (Rogers, 1973) and HCWs may find comfort in knowing that they are not alone in their difficulties. Kasket (2006) mentions the need for doctors to be in touch with their feelings, because being divided from one's own feelings makes it difficult to understand them and express them to others, which may contribute to deficient communication. This supports the findings of Aronson (2011) that being in touch with one's emotions and communicating them to other people can be learned, but that they are better absorbed from experience than from textbook reading. Aronson also argues that such learning will be most effective within a relatively safe, protected social environment where people can practise straight talking without fear that others will take advantage of their situation. The importance of being in touch with one's own feelings is explained by Hennezel (1998). By becoming aware of their emotions and why these are occurring, HCWs can create a distance between themselves and their own feelings and attitudes, and when they are able to do this, they no longer need to distance themselves from the patient (Hennezel, 1998). This type of self awareness also helps HCWs to distinguish between a relationship that is centred on the patient's needs, and one that is being used to fulfil the HCW's unmet needs. The latter would be considered overstepping boundaries, which is not only detrimental to patients, but can also interfere with the HCW's capacity to be objective (Williams, et al., 2005). However, a blurring of boundaries may occur, especially in palliative care. It is therefore crucial that appropriate training and supervision take place in a confidential and non-judgmental space where HCWs can feel safe enough to be honest about their difficulties and become mindful of their emotions (Nasrallah, 2009).

The Importance of Interdisciplinary Interventions

Medland (2004) created the "Circle of Care Retreat" a one-day interdisciplinary workshop with 150 team members with approximately 30 people in each group. Feedback from HCWs was positive in showing that increasing awareness and providing means to improve self care and life satisfaction can have an effect on improving attitudes towards the dying, and on relationships within the team. The retreat included subjects such as staying well, managing loss, developing stress management skills and strategies (such as relaxation, the use of a journal), facilitating bereavement, cultivating team effectiveness and group support and story-telling. The objectives of the intervention were to improve patient care through the well-being of HCWs, personally and as a team, and this was performed by convening an interdisciplinary group of care providers from all shifts and disciplines to interact in a nonclinical situation to discuss shared issues. Participants included staff from nursing, medicine, pharmacy, social services, psychology, physical therapy, and occupational therapy, as well as chaplains, grief counsellors, unit secretaries, patient liaison staff, and environmental and dietary service staff. Together, participants were able to examine the impact of stress on group support, cohesiveness, and effectiveness, to create staff awareness of positive coping strategies for use in situations of loss and during intense periods of stress and also to facilitate and give permission to each other to have fun at work.

It is important to note that Medland's approach was not just to teach ways of being present with patients with a terminal condition, but that attention was given to HCWs personally and as a team, which gave them the emotional preparation needed to be present and internally congruent with patients (Medland, et al., 2004).

The Need for Interventions to Be Supported by the Institution and to Occur within Monthly Working Hours

Studies on intervention outcomes and HCWs' needs have shown that training and emotional support sessions need to be incorporated within the workplace. HCWs who are tired and overworked will be reluctant to come to sessions or educational opportunities during their time off (Fillion, et al., 2005). This descriptive study involved 197 nurses who had devoted a portion of their work to palliative care over the last two years or more and answers to questionnaires showed that the main barriers towards attending workshops were loss of pay, attending in personal time, registration fees, lack of time, and the location. Factors facilitating attendance were attending during work hours, having the course paid for by the institution, or no registration fee, being freed to attend and their role replaced, and training at the workplace. Lafer et al. (2003) reported that mandatory overtime has a bad effect on nurses, which is another reason why support should be provided within the monthly hours of work.

2.5.4 SECTION SUMMARY

This section has considered a series of interventions designed for HCWs who care for patients with a terminal condition. These show that it is important to develop an intervention that evaluates simultaneously burnout designed specifically for HCWs who care for patients with a terminal condition, the quality of the helping relationship towards patients and families, death anxiety and personal and professional satisfaction.

It would also seem that interventions are more successful when several different teaching techniques are used and in association with self development to reduce death anxiety, when they are carried out in a non judgmental therapeutic atmosphere of group therapy open to all members of the team, regardless of their profession and when they are given during working hours not to interfere withHCWs' time-off.

2.6 CHAPTER SUMMARY

The first part of this chapter reviewed the literature in terms of the construction of the concept of burnout and different models. The different models were analysed around the main concepts their theories were based on, as can be seen in fig 1. Five main themes were found: personality, work environment, lack of control, meaning and existentialism and lack of coping mechanisms. Compassion fatigue is not a model of burnout, but was included in the diagram due to its relevance as a particular form of exhaustion in caregivers. The diagram presents the main concepts of each model, their main dimensions and how other researchers have developed these models and it ends with the mediation model of burnout, which can be seen as a synthesis of previous models and frameworks.

The second part of the chapter looked at causes for burnout in HCWs who care for patients with a terminal condition. Starting with the pioneer work of Mary Vachon, causes for burnout were separated into 3 main areas: personal, professional and institutional causes.

Within personal causes, death anxiety, which can interfere with the HCW's internal congruence when faced with death and dying, was manifested in three ways:

- Difficultly in coming to terms with existential issues regarding personal relationships and meaning in life;
- Difficulty in accepting death, loss of independence and physical degradation caused by aging and illness;
- Difficulty in coming to terms with unresolved grief or projected losses.

From the literature analysed in this chapter, the causes that contribute towards burnout most mentioned were interpersonal relationships, excess workload, bureaucracy, insufficient personal and vacation time, finding quality time to spend with the patient and dealing with upset and aggressive patients. These causes seem to be generalised as they are listed in the literature from a variety of countries. A cause for burnout mentioned in a nationwide Japanese study, was palliative sedation (Morita, et al., 2004), although this was not mentioned regularly in other studies.

Learning to accept the limitations of medicine was felt especially by physicians who were unable to stop the illness and by nurses when unable to change physician's attitudes, or when they have specialized training in palliative care, yet are unable to put it into practice, because they are not working in a palliative care unit, where the whole team share the same philosophy.

Coping with patients' and families' suffering and not having the time to grieve their death can also lead to burnout.

Professional causes of burnout were mainly communication difficulties with patients and difficulties within the team, such as giving bad news, avoiding the patient so as not to have to face difficult conversations, coping with difficult patients. Other professional causes were difficulties within the team, such as conflicts and lack of care for the team.

The institution and health care system can also prove to be a source of difficulty for the HCW. Ideally, palliative care teams and the referring team should work together for the benefit of the patient. However, this often does not occur. Excessive bureaucracy and disorganization within the team can affect the HCWs' motivation and an excessive workload due to lack of personnel, or bad organization can contribute towards exhaustion. Another difficulty faced by palliative care units is the lack of awareness of what palliative care is, on behalf of the society and government which has consequences at various levels, resulting in an increase in stress for HCWs who need to care for patients with a terminal condition all the same, but without the right conditions. Financial difficulties also affect the HCW because it may affect the quality of care given (medication, equipment, and training).

These causes for burnout are summarized in a diagram (fig 3) organized into personal, professional and institutional causes.

Many of the above mentioned causes for burnout can lead to internal incongruence, which may affect the quality of patient care. This shows a need for effective interventions. The final section of this literature review analyzed interventions that have been given to HCWs, taking into consideration the new framework for burnout in end of life care presented in fig. 5. i.e. interventions that provided one or more of the following characteristics: self development, self care, communication skills, and education on the psychological and spiritual dimension of patients with a terminal condition. These studies showed that interventions benefited if they were followed certain conditions as described in section 2.5.4. Following is a diagram (fig. 6) summarizing what this literature review found to be the optimal content, structure and format of an intervention to help HCWs cope with death and dying, maintaining their internal congruence. The part of the diagram, in grey, has been taken from the parts of the models of burnout in fig. 5, and internal congruence was added (in purple). Around these concepts are 3 nodes, which represent the main areas which this literature review has shown should be present in an intervention to prevent burnout in end of life care: personal development to increase personal well-being, training to increase the HCWs' sense of control and the recommended teaching methods and format of the intervention. Each of these nodes has subdivisions, which have been linked with the concepts from the burnout model (in grey), with the exception of 'workload'. Workload has not been linked to any concept in the interventions, but it is possible that an increased internal congruence could help HCWs cope with the stress caused by their excessive workload in a more constructive way. For example, links are shown between 'understanding the spiritual and psychological dimension and the needs of patients with a terminal condition' plus 'learning to integrate empathy and unconditional acceptance as part of one's way of being' and 'exquisite presence', because the former promotes the latter, and being able to give this type of quality presence will in turn lead to feelings of reward, supported expectations, and a meaningful existence, which in turn reinforces motivation. At the same time, learning to cope with death anxiety promotes internal congruence, and this is an underlying condition to be able to provide an exquisite quality of presence to patients with a terminal condition.

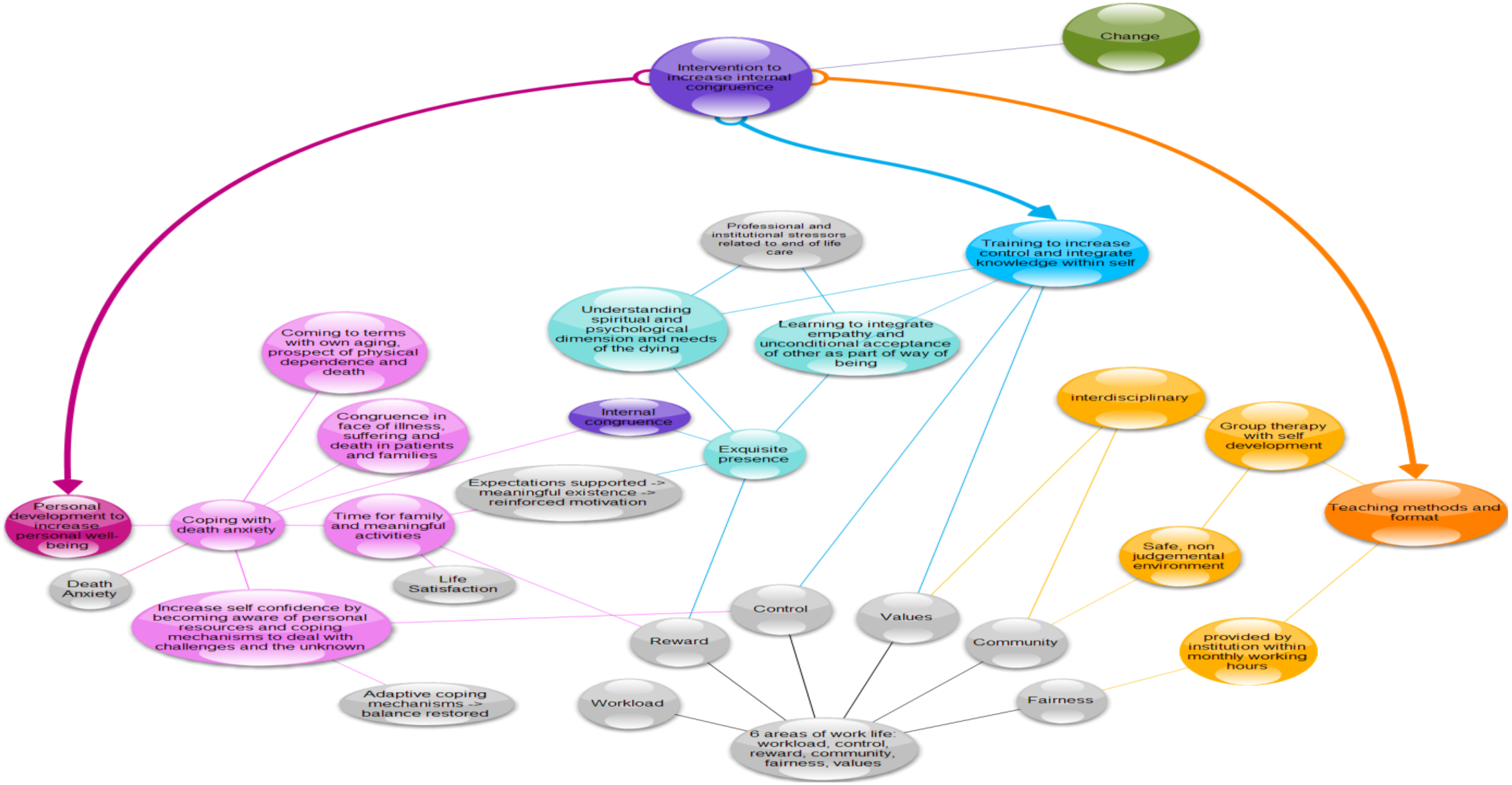


FIGURE 6 - INTERVENTION TO PREVENT AND REDUCE BURNOUT IN END OF LIFE CARE

3. METHODOLOGY

CHAPTER OUTLINE

This chapter describes the overall methodology and procedure used for this research. The first section of the chapter explains the design chosen and critically discusses why a mixed methods approach using the quasi-experimental design and qualitative interviews was considered the most appropriate for this study. The weaknesses of the quasi-experimental approach are discussed and what measures were taken to strengthen this study.

The second section describes the independent variable: the intervention designed to reduce death anxiety and burnout and increase the HCW's personal well-being and helping relationship skills. A description of the intervention is given together with its design, the acquired knowledge and skills it proposes to provide to the participants, and the teaching methodology used.

The third section explains which sites were used to recruit participants for the experimental and control groups.

The fourth section describes the methodology used for the sample. An explanation will be given for the number of participants the study aimed to achieve for the intervention group, the control group and for the interviews, and the inclusion and exclusion criteria used.

The fifth section describes the recruitment methods for the intervention group, the control group and the interviews.

The sixth section describes the instruments used to evaluate the HCWs' levels of burnout, helping relationship skills and personal well-being. A description is given of the three quantitative questionnaires, together with the rationale behind the open-ended questions and interview schedule.

The seventh and eighth sections describe the assessment procedures and data collection methods and the analysis frameworks for the quantitative and qualitative data.

The ninth section presents a timetable of each part of the research, showing what was done, when, and by whom.

Finally the tenth section discusses ethical issues.

3.1 DESIGN AND OVERVIEW

3.1.1 AIMS AND OBJECTIVES

This research used a mixed methods approach, using a quasi-experimental pre-test, post test non equivalent group design (experimental and control group) for part of the participants and a pre-test, post-test single group design (no control group) for the remaining. Quantitative questionnaires and open ended questions were used together with qualitative interviews. The aim was to evaluate the effect of an intervention which consisted of training specially designed to reduce burnout and death anxiety for health care workers who care for patients with a terminal condition, both in and out of palliative care. The study was based in Portugal and the interventions were given from October 2005 to February 2008. The qualitative interviews were performed during 2008.

The following section will explain the outline of the design, why the quasi-experimental design was considered to be the most appropriate, and will also identify the limitations of this research and the measures taken to improve the validity of the design.

3.1.2 DESCRIPTION AND DISCUSSION OF THE QUASI-EXPERIMENTAL DESIGN

The main methodological approach was to use the quasi-experimental design and this section will provide a critical review of this method. This will be followed by an account of how the design for this study was constructed in the light of the literature.

Although designs involving pure randomized controlled trials are considered to be the most robust in research (Grimshaw, et al., 2000), this is not always possible in the real world and social science research, due to practical or ethical barriers (Simon & Higginson, 2009), and therefore, one needs to accept limitations and do the best within the existing circumstances. Even without randomized experiments, it is still possible to perform quality research using other designs.

Quasi-Experimental Designs

Quasi-experiments were being used in studies as early as 1916. Thorndike, et al. (1916), referred to them as ‘unrandomized rotation experiments’, which were introduced to achieve some degree of control where random assignments to equivalent groups were not possible. Campbell and Stanley (1963) designated this unrandomized rotation experiment as part of the group of quasi-experimental designs.

Quasi-experiments share the same purpose as other experiments, which is to test descriptive causal hypotheses about manipulable causes, but, although they may use similar structural details such as ‘control groups, pre-test and post-test measures to support a counterfactual inference about what would have happened in the absence of treatment’, this design does not use random assignment. Participants are assigned to groups either by self selection or by administrator selection (Shadish, et al., 2001). However, although there is a lack of randomization in relation to when and whom to expose the scheduling of the experimental stimuli, it is still possible to use an experimental design in the scheduling of data collection procedures: the when and to whom of measurement (Campbell & Stanley, 1963).

The disadvantage of such designs is that there is a need to rule out alternative explanations for the observed effect. For example, if the control and experimental group were not randomly chosen, there may be slightly different characteristics between these two groups. It may therefore be unclear as to whether the observed effects that occurred in the experimental group and not in the control group were due specifically to the treatment, and not to inherent differences between the groups. There is a need therefore in quasi-experiments to enumerate plausible alternative explanations in the light of existing theory and then use logic, design and measurement to assess if these could be the reason for change, rather than the intervention. Shadish et al. stress the need to enumerate only plausible explanations, because listing all possible alternatives could be endless (Shadish, et al., 2001). The disadvantages of quasi-experimental designs will be addressed after the following explanation of the different types of designs and explaining which was considered the most appropriate for this study.

Quasi-experiments are particularly useful for research performed in the real world, but where there is a desire to maintain an experimental format. This is often the case in the social sciences that deals with research in a less controlled environment than a laboratory (Robson, 2002). Robson mentions several types of quasi-experiments, all involving non-random assignment of participants: pre-experimental designs, interrupted time series designs, regression-discontinuity designs and pre-test post-test non-equivalent group designs:

- Pre-experimental designs include two types: single-group and non-equivalent group post-test only designs. Robson advises to avoid these, as there are no means of comparing with a pre-test status. A third type of pre-experimental design is the pre-test, post-test single group design. The weakness of this design is that although it is possible to compare with a pre-test status, the absence of a control group eliminates the possibility to evaluate what would have happened in the absence of the intervention. Grimshaw et al. (2000) also suggests that the results of studies with these types of designs may overestimate the effects of interventions and that the observed effects from uncontrolled studies were greater than those from controlled studies.

- Interrupted time series designs involve a single experimental group on which a series of measurements or observations are made before and after an intervention. It requires a dependent variable on which repeated measures are taken. Grimshaw et al. (2000) suggest that to obtain reliable results, 20 data points are needed before the intervention and 20 data points after are needed. This can prove difficult and impractical to carry out unless it is part of routine data sources. They argue that many published interrupted time series have been analysed inappropriately, resulting in an overestimation of the effect of the intervention.

- Regression-discontinuity design, where participants are attributed to an experimental or control group according to the results of a pre-test being below or above a determined criterion. The results after the experimental intervention will provide evidence for its effectiveness.

- Pre-test, post-test non-equivalent group designs, involving either two or more groups, one of which could be the control group. The control group should have similar characteristics and performance as the experimental group and the data should be collected contemporaneously using similar methods before and after the intervention as is given to the experimental group. Between-group analyses comparing both groups are undertaken and any observed differences are assumed to be due to the intervention. (Grimshaw, et al., 2000).

Harris et al. (2006) suggests that, the soundest of these designs is the interrupted time series design, followed by the pre-test, post-test non equivalent group design, where one of the groups is a control group and Simon and Higginson (2009), suggest that the most commonly used designs are the before and after without control group, which are very vulnerable to secular (temporal) trends (change occurring due to the passing of time and not due to the intervention). However, contrary to this view, a review of the literature for research using quasi-experimental designs specifically to evaluate interventions showed that most frequently, the pre-test, post-test non equivalent group design was used (Ewers, et al., 2002; Mallory, 2003; Costantini, et al., 2003; Steginga, 2005; Fineberg, 2005; Kurz & Hayes, 2006; Smith-Cumberland, 2006; Doyle, 2007; Le Blanc, et al., 2007; Ramsay, et al., 2007; Sun, et al., 2011). Considering that this design is considered one of the soundest, and has been chosen by other similar and significant studies, the pre-test post-test non equivalent group design was also considered for this study.

Following sections outline the use of the quasi-experimental design in this study:

- The use of pre-test, post-test

To evaluate the effectiveness of the intervention given in this research, three questionnaires were used to gain perceptions of the quality of participants' helping relationship with patients, their level of burnout, and their level of well-being on two occasions: immediately before training (time 1 (real) – T1), and four months after training (time 2-T2). At the same time as T2, participants were also asked to assess their perception of how they thought they were before the training (time 1 (perception) - T1p) in order to evaluate if the training had changed their criteria of self-evaluation. Death anxiety was also assessed using one factor from the quality of helping relationship questionnaire and the well-being questionnaire. Further qualitative analysis was undertaken of the free comments from the questionnaires and of data from the interviews. Both the intervention and the instruments used will be discussed in detail below.

The independent variable was the intervention and the dependent variables were the participants' levels of burnout, quality of helping relationship, personal well-being, and death anxiety. Results were also considered in relation to the participant's age, profession, and workplace. Gender was not considered, as 89 per cent of the group was female. The paragraphs below will explain the choice of pre-test, post-test designs considered.

- Assignment to groups by self-selection rather than randomized trial

The clinical directors of 22 units that cared for patients with a terminal condition, both in and out of palliative care and in various parts of Portugal were contacted to participate in the intervention by written invitation with a full explanation of the research (see appendix nº 17). Ten units accepted. The research was explained to the unit's team members either by the clinical director or by the head nurse and subsequently, each team member agreed to participate or not, thus assignment was by self-selection and not randomized trial, which is one of the criteria for choosing quasi-experiments over randomized trials (Shadish, et al., 2001). However, as mentioned above (Campbell & Stanley, 1963), an experimental design was still possible in the scheduling of data collection procedures.

Randomization was also not considered for ethical reasons related to withholding a beneficial intervention to half the sample as raised by Harris et al. (2006) and practical issues, as shown in the study by Ewers et al. (2002). These issues will be elaborated upon in the discussion.

However, lack of randomization and the characterization of the sample also raised the question of the generalizability of the study. As subjects were not chosen randomly and were only from Portugal, the results of the study are only generalizable to the populations that were assessed: Portuguese HCWs who care for patients with a terminal condition. Mallory (2003), who encountered a similar problem, compensated for this by involving different institutions to provide the opportunity for sound research differentiation. The same was attempted in this study by using different institutions and institutions from different parts of the country as can be seen in the sample section.

- The control group and the use of pre-test, post-test non-equivalent groups design together with pre-test, post-test single group design

The quasi-experimental design was also considered the most appropriate for this study, for reasons related to the control group.

The intervention was given to HCWs from two experimental groups: those working out of palliative care units (EG1) and those working within (EG2) and results were compared between these two groups. However, it was not possible to have a control group (CG) for both experimental groups. Only EG1 had a control group. No control group was used in the case of EG2 as it was not possible to ensure that they received no other palliative care training between time 1 (T1) and time 2 (T2). Therefore, one can consider that two quasi-experimental designs were used: the pre-test, post-test non-equivalent groups design for HCWs who work out of palliative care units, and the pre-test, post-test single group design for HCWs working in palliative care units.

The constitution of the control group was another reason for choosing the quasi-experimental design. The control group did not comprise the same numbers and characteristics of participants as the corresponding experimental group. Costantini et al. (2003), and Le Blanc et al. (2007), overcame the problem of different characteristics by using a larger control group than experimental group to compensate for these differences. However, the attrition rate can be a setback as mentioned in the study by Kurz and Hayes (2006). The attrition rate can be even more pronounced in the case of control groups where no intervention is given, thereby reducing their commitment to the research study. Ramsay (2007) overcame this problem by comparing their results to the results of a control group of another similar study. This study intended to use the same approach as Costantini et al. and Le Blanc, by inviting a larger control group to participate in the study than the experimental group.

Weaknesses of Quasi-Experimental Designs

The different problems that can occur with quasi-experimental designs have been analysed by different authors as will be shown below. These are mainly threats to internal validity, which may be defined as the degree to which observed changes in outcomes can be correctly inferred to be caused by an exposure or an intervention (Harris, et al., 2006). Thus internal validity occurs when a researcher controls all extraneous variables and the only variable influencing the results of a study is the one being manipulated by the researcher, so that the variable the researcher intended to study is indeed the one affecting the results and not some other, unwanted variable. Campbell and Stanley (1963) mention 8 main threats to internal validity:

1. History (events, other than the experimental treatments, influence results);
2. Maturation (during the study, psychological changes occur within subjects);
3. Testing (exposure to a pre-test or intervening assessment influences performance on a post-test);
4. Instrumentation (testing instruments or conditions are inconsistent; or pre-test and post-test are not equivalent, creating an illusory change in performance);
5. Statistical regression (scores of subjects that are very high or very low tend to regress towards the mean during retesting);
6. Selection (systematic differences exist in subjects' characteristics between treatment groups);
7. Experimental mortality (subject attrition may bias the results);
8. Diffusion of treatments (implementation of one condition influences subjects in another condition).

To these, Shadish et al. (2001) added a ninth: ambiguous temporal precedence (Lack of clarity about whether the intervention occurred before the outcome).

Cook and Beckman (2008) argue that a comparison group can help mitigate many of these threats, and that randomization is only required to control threats from selection and maturation; it does not control for mortality, location, attitude or implementation threats.

However, Grimshaw et al. (2000) argue that the pre-test, post-test non equivalent group design (i.e. using a comparison group as suggested by Cook and Beckman (2008)) also have their drawbacks because it is often difficult to obtain a control group that is comparable and well matched to the study group due to differences at baseline levels. This baseline imbalance suggests that the control group may not experience the same secular trends or sudden changes as the intervention group, thus questioning any apparent effect of the intervention. In order to control this weakness, baseline studies will be performed between the experimental and control group. Grimshaw et al. (2000) also suggest that there is no direct comparison between the two groups and that the usefulness of controlled before and after studies is also limited because the estimate of effect cannot be attributed to the intervention with confidence due to the non-randomized control group. They argue that with before and after designs, randomised trials could be performed just as easily and would provide a more reliable estimate of effect.

These weaknesses of the quasi-experimental method have been acknowledged in other studies. The study by Mallory (2003) raised the question of the pre-test possibly affecting the results of the post-test, by raising awareness of the problem which could cause change to happen in between the two tests, implying that post-test only may be a stronger design. Doyle (2007) found that this threat to internal validity called ‘testing’ caused a ripple effect in his control group, however, pre and post-test differences were not significant. However, Cook and Beckman (2008) argue that the post-test only design is only inherently stronger than the pre-test post-test design if the design is randomised and the sample sufficiently large, which is not the case in this study. Finally, this was also not considered a problem for the control group, because even if the pre-test did affect the results of the post-test, it would be in the direction of improving the results, which is contrary to the purpose of what the control group is trying to show.

Mallory (2003) also regarded the instruments used in her research as being unable to identify all previous death experiences and death education that may have an impact on attitudes towards care of the dying. This was also the case in this research. It was not possible to be absolutely sure that participants were not subject to any other form of education, or that maturation, another threat to internal validity, did not play a role. To compensate for this weakness, an interval of four months between questionnaires was chosen because this was considered long enough to allow the participants to reflect on the contents of the intervention and assimilate changes (Kurz & Hayes, 2006), rather than show positive changes due only to momentary enthusiasm immediately after the course, yet also short enough to reduce the effects of maturation and minimize the possibilities of other interventions taking place.

Stephan (2006) highlighted the differences between practitioners and researchers and the complexities of being both, which may also present another threat to internal validity, as was the case in this study. He suggested that whereas practitioners are fundamentally action-oriented people engaging in activities leading to improvements in the real world, researchers mostly work in an environment where research is valued more than the extent to which their findings are adopted by practitioners. He explained that practitioner-researchers require training in both areas capitalising on their awareness of psychological processes and tuning these to a greater precision in the research methods and measurements should be practised by practitioners when undertaking research. In this study, although the researcher had been regularly involved in research since her university degree, her main activity is psychotherapy and therefore, during the intervention, there was a need to maintain awareness of what is required in academic research. A further challenge is articulated by Stephan in that practitioners who are also researchers of their interventions “are deeply concerned about the effectiveness of their techniques” (Stephan, 2006, p. 599). This may lead to a conscious or unconscious biasing of research techniques to achieve a successful outcome. There was a need therefore for this therapist to detach herself from the role of researcher during the intervention and be centred solely on the participants and simultaneously be aware at all times not to “promote” the intervention in any way that may influence the participants’ feedback whilst filling in the questionnaires and during interviews. Reflective sessions with the supervisor also served as a ‘check’ against this potential tendency, where approaches and data collection techniques were examined (Pope & Mays, 2006).

Ewers et al. (2002) discussed the issues of researcher/facilitator in their study on whether psychosocial interventions reduce burnout rates in forensic nurses: the principal researcher and the facilitator of the intervention was the same person, which could have been considered a threat to unbiased evaluation. This was however not considered a significant drawback as it was the opinion of the authors of the study that the significant improvements in attitudes towards clients were due to enhanced understanding of the nature of the illness, implying that this would occur regardless of the nature of the facilitator. Ewers et al. (2002) also discussed the ethical problems when the researcher undertakes research in addition to their already established role within the institution. They suggested that the research may involve individuals of lesser power or status confronting colleagues with higher status. Ethical issues may also arise when information obtained from the research is made public which can lead to conflict within an institution or compromise the privacy or professional status of the participants. (Human Research Ethics Office, 2008).

Within this research study, there was a similar issue, as the first part of each intervention was given by the researcher in her role as therapist However, unlike the study carried out by Ewers et al. (2002) there was no previous working relationship between the researcher and the participants which could have resulted in a power-over relationship, where the participants could have felt coerced to provide positive feedback, although this may also occur out of a desire to be helpful. Efforts were therefore made to minimize any bias by assuring the participants that their feedback in both quantitative and qualitative feedback would be anonymous, and by explaining that part of the research was to evaluate the intervention and therefore, negative feedback would be equally important, in order to implement improvements. A second measure taken was to have an external psychotherapist perform half of the interviews, as described below in the section 3.7 on “assessment procedures and data collection”.

Finally, similar to studies by Steginga (2005), Fineberg (2005) and LeBlanc (2007), the instruments in this research only measured perceived rather than objective levels of burnout, helping relationship skills and personal well-being. Measures were taken to overcome this drawback firstly by ensuring that the intervention given to the experimental group was designed according to the theory related to the needs of HCWs who care for patients with a terminal condition, thereby focusing on concrete difficulties and skills and secondly, by carrying out qualitative interviews to obtain a better understanding of whether they confirmed the quantitative results.

In summary, this study used a pre-test, post-test non equivalent group design for EG1 and a pre-test, post-test single group design for EG2. A four month interval was given between tests to provide enough time for significant changes to occur, rather than momentary enthusiasm. Assignment to groups was by self selection, rather than by randomized trial. Different institutions covering the north, centre and south of Portugal were included in the study to improve generalizability.

Although research using quantitative methods has been preferred over qualitative methods (Glasby & Beresford, 2006) and there has been a concentration and financial investment in promoting the use of quantitative research evidence (Stevens & Ledbetter, 2000), Moriarty, et al (2007) argues that drawing on a diverse source of information can be useful, but that unfortunately qualitative forms of evidence are often excluded from many electronic databases and viewed as untrustworthy. Robson (2002) refers to this as the ‘paradigm wars’ between positivists (empiricists, quantitative researchers) and constructionists (phenomenologists, qualitative researchers). However, Billings (2013) argues that academics are now accepting a more eclectic view and that researchers have demonstrated that evidence can be incomplete without drawing from diverse sources (Long, et al., 2006; Moriarty, et al., 2007; Billings, 2013) and adds that a pluralist view, recognising the equality of different data sources is being increasingly recognised, as is the importance of triangulation of data. Triangulation of data has been defined as checking the results of a qualitative method with those of a quantitative method, or vice versa (Robson, 2002).

3.1.3 USE OF MIXED METHODS APPROACH

Taking into consideration the above views, a mixed methods approach was used to strengthen the design of this study, by combining qualitative with quantitative methods. Research literature distinguishes between multi-method and mixed method studies. Whereas multi-method studies use different methods of data collection and analysis within a single research paradigm (quantitative or qualitative), the mixed methods studies aim to bring together methods from different paradigms (Spratt, et al., 2004). However, this distinction is not always made as these two concepts have been referred to in the past as one and the same (Stange, et al., 2006). Following the definition of Spratt et al. (2004), this study used the mixed methods approach, combining the above described quantitative quasi-experimental design with qualitative open-ended questions and interviews. A strong reason for opting for this approach was to obtain more personalised information from the participants by being ‘closer’ to the participants, as stated by Glasby and Beresford (2006). Billings (2013) emphasizes that an experimental approach cannot always identify specific reasons for why changes occur, and that a wider spectrum of evidence including qualitative sources needs to be embraced in order to be able to develop methods that can fully describe and analyse the object of the research. Therefore, to fully understand the benefits and weaknesses of the intervention, a close dialogue with some of the participants was deemed necessary in order to achieve a balanced interaction between the quantitative and experiential data.

The qualitative methods used are described below.

Qualitative Methods

Qualitative data for the study were derived from three distinct sources and points in time during the project and will be described and rationalised below.

Initial Assessment of Difficulties

At the beginning of each intervention, the group was asked to verbalise their difficulties in caring for patients with a terminal condition. As they spoke, these were written on the blackboard by the facilitator. The aim was to understand the specific difficulties of each group which would allow the facilitator to focus on these difficulties during the 6 day intervention. It was also a means to give a qualitative understanding of the participants’ pre-intervention status and a means to compare with post-intervention qualitative results. Each difficulty was only written down once, even if it was shared by more than one member of the group. These items were then taken note of before being erased from the blackboard and subsequently written in word. At the end of the 29 interventions, the Word document was then put into NVivo format and the difficulties were categorised.

Open Ended Questions

In the post-intervention quantitative questionnaires, a series of open ended questions were presented for the participants to answer in writing. The rationale for including open-ended written questions and their content will be justified below, in the instruments section.

Interviews

Semi-structured interviews were carried out with a limited amount of participants from the experimental group. King (1994) explains that there are several circumstances in which interviews are appropriate one of them being where quantitative studies have been carried out and qualitative data are needed to validate particular measures or to clarify and illustrate the meaning of the findings, as is the case in this study. Robson (2002) described three types of live interviews, the fully structured interview, the semi structured interview and the unstructured interview. The fully structured interview was not considered useful in this case, because the written open-ended questions on the post-test questionnaire were already structured, containing pre-determined questions with fixed wording in a set order. The purpose of the interview in this study was to provide the flexibility needed to allow for other information to emerge. This requires sensitivity on behalf of the interviewer to follow-up interesting responses or to investigate underlying motives. An unstructured interview was also not considered useful, because, as argued by Powney and Watts (1987), these may be merely informant, and mostly controlled by the interviewee. Some amount of control was needed to ensure that the necessary information was received to complement data from the questionnaires and to compensate for the weaknesses of the design in relation to randomization and the characteristics of the control group, which were not strictly the same as the experimental group. An interview would allow the researcher to obtain a deeper understanding of whether effects that occurred in the experimental group and not in the control group were due specifically to the treatment, and not to inherent differences between the groups.

3.2 THE INTERVENTION

3.2.1 DESIGN AND AUTHOR OF THE COURSE

The training was based on a course conceived by Hermine Aitken, (Aitken, 2011) a health counsellor trained in France by Remy and Anne Marie Filliozat, (SA-MA-SA, 2012) and followed the teachings of Carl Rogers (1951), Elizabeth Kubler-Ross (1970), Ira Byock (1996), Hennezel & Leloup, (1997, 2008), Marie de Hennezel (1998), Remy and Anne Marie Filliozat (2006) and Rauch & Muriel (2006). It was called "Life and Death, the Same Preparation" and consisted of personal development and theoretical and practical training in caring for patients with a terminal condition. The duration of the course was 36 hours in duration divided into two 18-hour modules over 6 days (3 days in each module). The training was given in a training area of the institutions.

The philosophy behind the course followed the findings of the literature review, that HCWs in palliative care need to be able to enter into a close, empathic and meaningful relationship with their team members, patients and family, both adults and children and simultaneously maintain their internal congruence. Patients with a terminal condition face strong existential, spiritual and emotional issues that can cause the HCW to feel uneasy, helpless or remember their own personal issues. One way of dealing with this, is to create an emotional distance between them and the patient and his/her family, rather than just a healthy professional distance. This may interfere with real empathy, which is not beneficial for the patient, and may contribute towards feelings of professional insufficiency for the HCW and eventually lead to burnout. Becoming fully aware of these existential issues in their own lives will allow the HCWs to recognize, understand and integrate their own feelings, while still continuing to be fully present in the moment and centred towards the patient. Learning to develop self-awareness is therefore a powerful tool for self-care. Therefore, as mentioned in section 2.4.4, in order to emotionally prepare HCWs to provide quality care for patients with a terminal condition, without suffering from burnout, there is a need for an intervention that includes the variables of

- Burnout designed specifically for HCWs who care for patients with a terminal condition;
- Quality of the helping relationship towards patients and families;
- Death anxiety;
- Personal and professional satisfaction,

and that this be carried out in small groups to allow for individual attention for each participant to work on their difficulties. It is in this that our intervention differed from others: two separate modules were created within the intervention, with a maximum of ten participants to allow for individual attention, the first being in the form of group therapy to facilitate theself-development of the participants, and the second to focus on the patient and family.

In the first module a space was created that would allow the HCWs to examine within themselves, the same fears that patients with a terminal condition are faced with. In other words, the training they received for the benefit of the patient was first given to them, for their own benefit. The first module was conducted in a group therapy format to facilitate personal introspection on death anxiety and existential issues, thereby increasing participants' serenity and capacity to participate in a helping relationship where death and suffering are very present. The approach was changed, with Aitken's consent, from a psychoanalytical approach to the Person-Centred Approach practised by the facilitator (Rogers, 1951) by removing certain exercises and content which were not congruent with the person-centred approach or the findings of the literature review. Participants were given space to reflect on the quality of their personal relationships, the meaning of their lives, their coping mechanisms when faced with suffering and the unknown, and the prospect of their own ageing and physical degradation. The aim was not only to help HCWs to better understand their own personal issues but also to improve their capacity to empathize with patients, as these existential issues also affect patients with a terminal condition. This can be illustrated in the following diagrams:

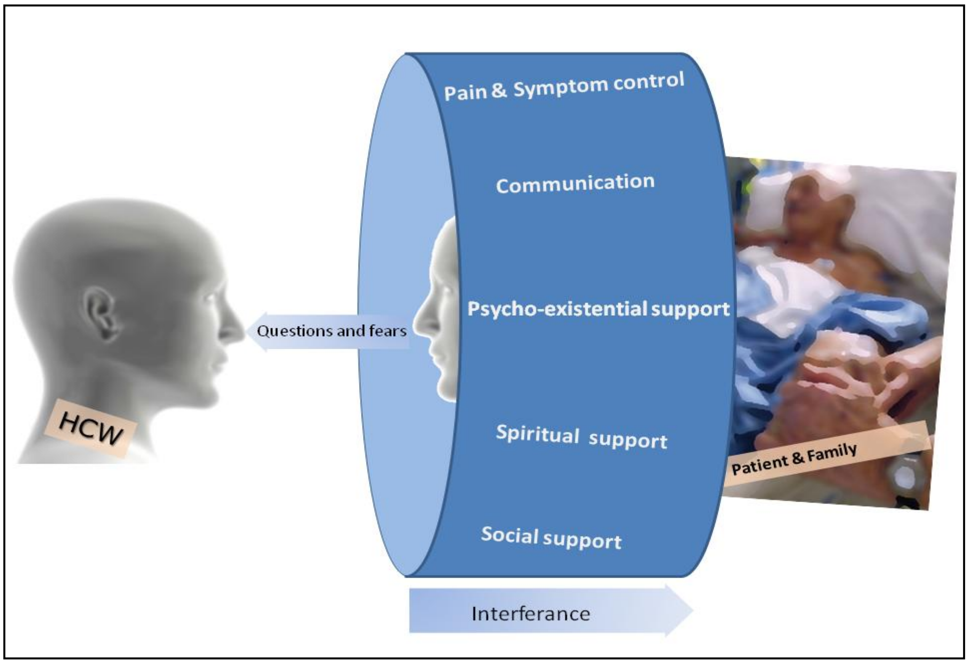


FIGURE 7 - HCWS QUESTIONS AND FEARS CAUSE INTERFERENCE IN THE RELATIONSHIP

The HCW is seen looking through a relationship tunnel to the patient and his family. On the outside of the tunnel, are all the different dimensions of patient and family care. However, there is interference: all the patients' and families' fears are mirrored back to the HCW, and blocks the way for a real meaningful relationship, without any avoidance mechanisms.

The following illustration shows the first part of our training. The centre of the training is not the patient and family, but the health care worker and their team. They share and work on their fears of dealing with death and suffering, they experience what good communication is about: non-judgmental listening, understanding, being genuine, they talk about meaning in their lives, their spirituality, and their relationship with family and friends. It is accepted that not all the HCWs' fears will disappear, but they will become aware of them, and this will help them to manage their feelings, and also, to understand the other person much better. Another advantage is that the HCWs will accept their own vulnerabilities, and this will place them on the same level as the patient: one vulnerable (but congruent) person relating to another. This is a good starting point for a helping relationship.

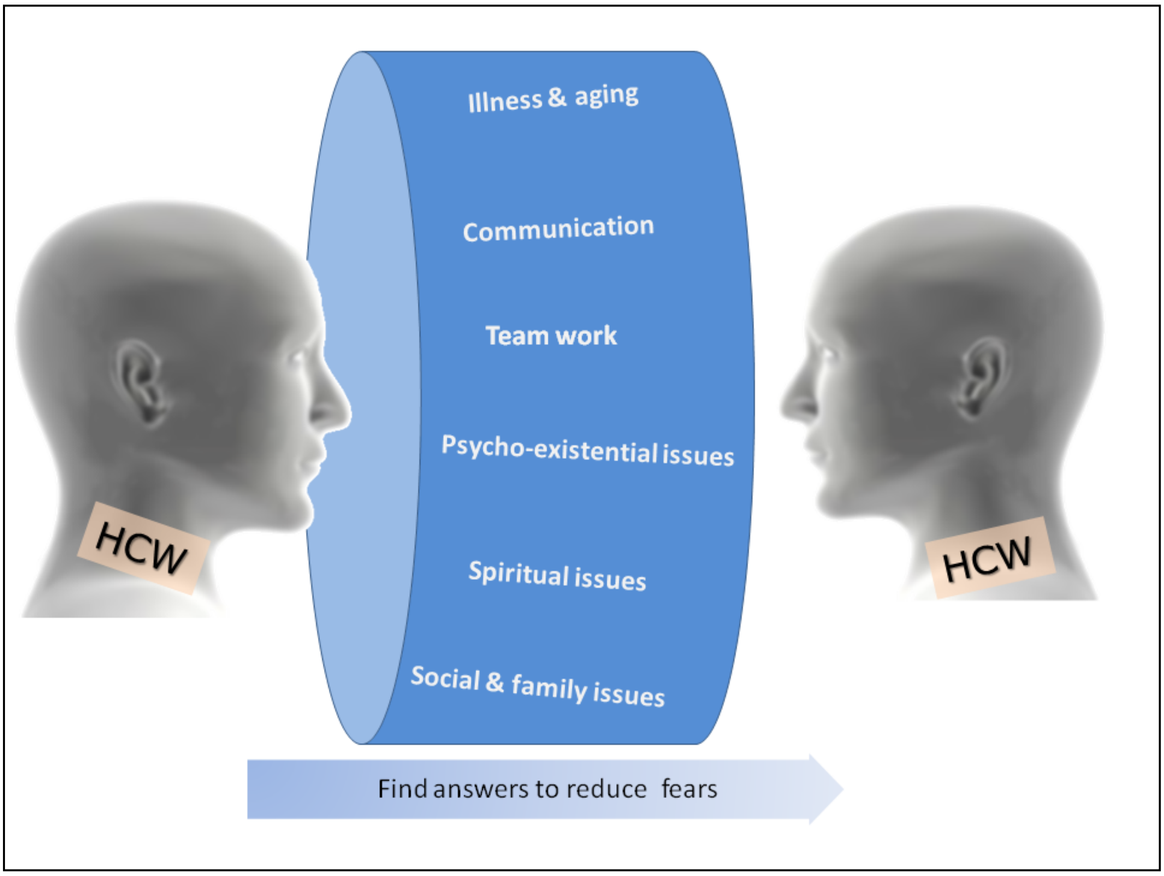


FIGURE 8 - THE INTERVENTION HELPS HCWS TO FIND ANSWERS AND REDUCE FEARS

Finally, the last illustration shows a HCW who has worked on his own fears, has learnt about how to help the patient, and who is now freer from internal conflicts and capable of entering an effective, compassionate and fulfilling helping relationship with the patient and family.

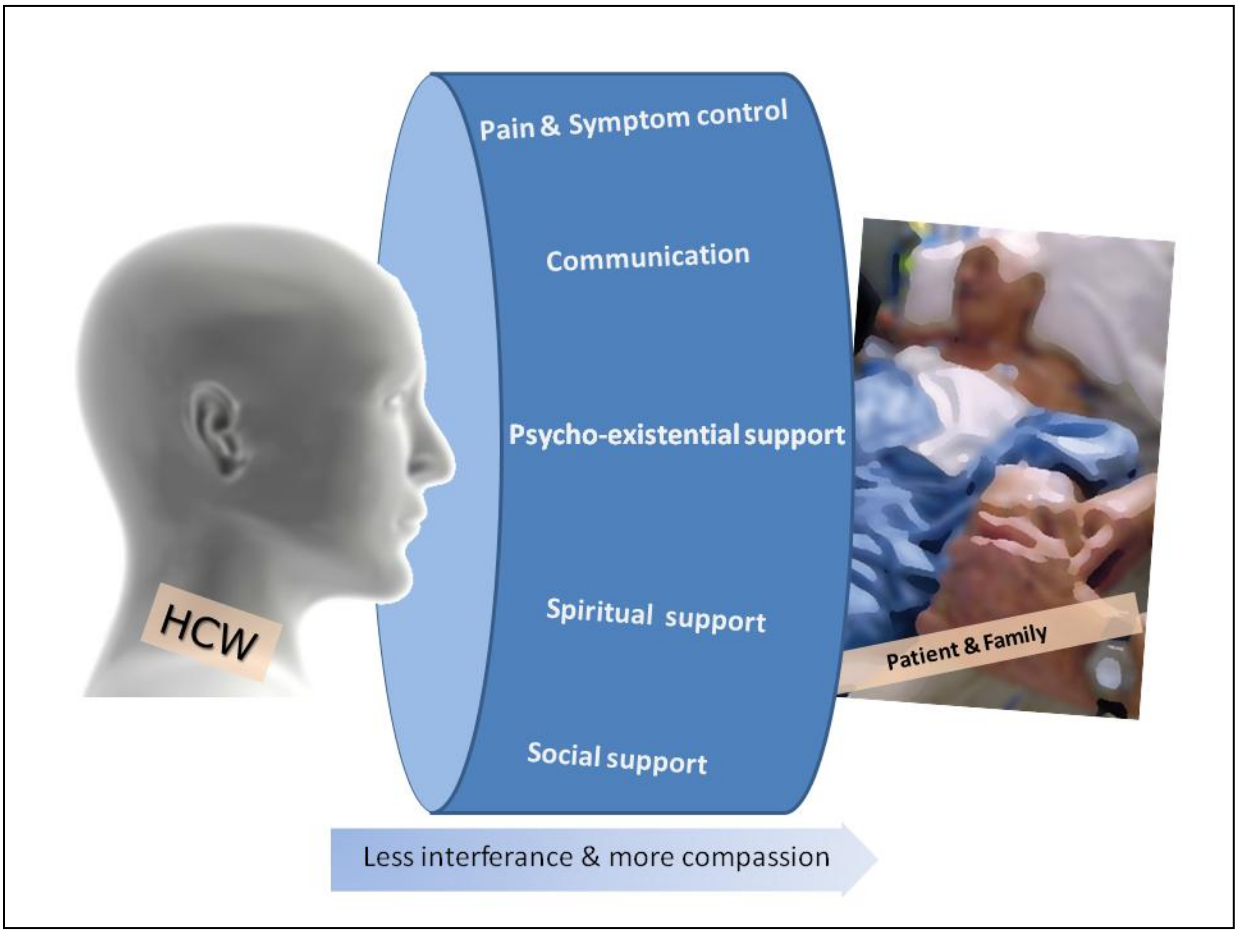


FIGURE 9 - AFTER THE INTERVENTION, HCWS ARE ABLE TO EXPERIENCE LESS INTERFERENCE AND MORE COMPASSION

The second module covered theoretical information and involved practical exercises for improving communication skills and understanding the psychological and spiritual needs of patients with a terminal condition.

The first module was offered by a psychologist trained in person centred therapy and the second by a trained holistic health counsellor.

Following is a more detailed description of the content of the course. This content has been drawn from my own work published in Junger & Payne 2011:

3.2.2 ACQUIRED KNOWLEDGE

- Understanding of existential issues that affect patients with a terminal condition, and their families;
- Understanding of our own resolved and unresolved existential issues;
- Understanding of the influence of one's own individuality (personality and temperament traits, etc.) on the relationship with patient;
- Understanding the meaning of our role as professionals who care for patients with a terminal condition and their families;
- Relaxation and meditation techniques to manage stress;

- Understanding of grief and bereavement in patients with a terminal condition and their family;
- Understanding of patients' spiritual needs;
- Basic understanding of Person Centred Therapy.

3.2.3 ACQUIRED SKILLS

- Capacity to empathize with the patient and family in a close and meaningful relationship and simultaneously maintain one's own internal congruence;
- Capacity to be aware of one's own existential issues and those of the patient, as well as the effect these can have on one's own feelings;
- Capacity to detect symptoms of burnout in any of its dimensions in ourselves and seek help when needed;
- Capacity to maintain physical and emotional presence with a patient suffering from physical pain and degradation;
- Capacity to perform relaxation techniques on self to manage stress;
- Capacity to make meaningful questions regarding the care we provide;
- Capacity to work in a team, giving and receiving to and from it;
- Capacity to provide emotional and spiritual care for the patient and family.

3.2.4 METHODOLOGY

- Sharing within group therapy;
- Practical exercises that promote reflection and self-awareness;
- Creating a team vision;
- Relaxation sessions;
- Role-playing;
- Psychodrama;
- Exercises of active listening.

3.2.5 THEMES APPROACHED

Self-Reflection / Self-Awareness

Physical: my own Body

- Self-care: what am I doing to keep myself physically healthy? (diet, exercise, relaxation);
- Natural aging: accepting signs of aging, loss of beauty;
- Dealing with the prospect of losing independence and mobility. Accepting dependency on others;
- Dealing with the prospect of living with: physical degradation, deformity and pain;
- Acknowledge ones own feelings when caring for patients suffering from physical degradation, deformity and pain;

- Dealing with the acceptance of one's own dead body: how do I imagine my body after death; how would I like my body be treated after death;

Existential Issues: Emotional and Spiritual

- State of relationships with loved ones: meaningful relationships, communication and expressing feelings with loved ones; time dedicated to family and friends; issues of forgiveness and gratitude; how would I like to be remembered after my death, and what am I doing to contribute towards this?
- My role in my family: being a child, a parent, a relative and my different reactions in the presence of my loved one's suffering;
- Capacity of being alone: how do I deal with emotional/physical suffering when alone? Do I feel helplessness or have resilient strengths? Being alone while suffering is a different concept than loneliness (which can also be experienced when someone is present);
- Living life with meaning: do my present activities contribute towards a sense of fulfilment and meaning? Am I wasting a lot of time on activities that are meaningless to me? What are my goals in life? What is really important to me? If I knew I were to die shortly and looked back on my life, would I have a sense of having lived well? If not, what can I change?
- Issues of uncertainty and lack of control in life: not everything is under our control in life. How do I deal with uncertainty? What are my personal resources and coping mechanisms to deal with difficult situations in life? An analysis of past life obstacles (any loss, difficulty in life, or traumatic experience) and how we dealt with them will help us get to know our personal strengths and knowing our resources may reduce fear of the unknown;
- Personal bereavement issues: am I in bereavement? When someone I loved died, what were my needs, or what do I think my needs would be if someone died? What would I need around me for this to happen?
- My own death: if I were dying, what would I like to be feeling? What would I need around me for this to happen?
- Dignity: what are my cornerstones of dignity? When is my body in dignity, when am I in dignity? How can I facilitate dignity tutelage and preservation in patients and caregivers?
- My own religious and spiritual beliefs and needs: understanding the difference between beliefs and certainties; my religion and my spirituality; how do I nurture my spiritual self? Ensuring that our spiritual beliefs and needs are not imposed on our patients;
- Motivational issues: why did I choose to work in palliative care? If it just happened (and I did not choose): where does my work motivation stem from? Work motivation in palliative care as a process.

Helping Relationship:

- Five stages of grief – Elizabeth Kübler-Ross;
- Bereavement in adults and children;
- Spiritual needs of patients with a terminal condition;
- Active listening and how to develop a quality of presence within the relationship.

3.3 SITES

The training was given in institutions that care for patients with a terminal condition in different parts of Portugal to obtain diversity in the coverage of patients. In order to obtain maximum participation, a large number of institutions from the North to the South of Portugal were formally approached to participate in the intervention group of the research by means of a letter of invitation (see appendix 17). Following is a list of the institutions that were approached:

Palliative Care Units:

1. Intra-Hospital Palliative Care Unit of the Portuguese Institute of Oncology – Lisbon - Centre
2. Hospital do Mar – Lisbon – Centre
3. Centro de Saúde de Odivelas – Lisbon – Centre
4. Unidade de Cuidados Paliativos da Santa Casa de Misericória de Amadora – Lisbon - Centre
5. Unidade da Santa Casa de Misericórdia de Azeitão – Azeitão – Centre
6. Casa de Saúde da Idanha – Lisbon – Centre
7. Intra-Hospital Palliative Care Unit of Hospital de S. José – Lisbon - Centre
8. Palliative Care Unit of the Portuguese Institute of Oncology - Coimbra – North/Centre
9. Palliative Care Unit of Hospital do Fundão – Fundão – North/Centre
10. Palliative Care Unit of the Portuguese Institute of Oncology - Porto – North
11. Palliative Care Unit of the National Network of Palliative Care – Porto – North
12. Intra-Hospital Palliative Care unit of Hospital S. João – Porto – North

Non-Palliative Care Units that care for patients with a terminal condition

1. Dr Maria José Palma – responsible for Community Network of Palliative Care in the Alentejo – Centre-South
2. Centro de Saúde de Loulé – Loulé - South
3. Centro de Apoio Social de Oeiras – Lisbon – Centre
4. Curry Cabral Hospital – Lisbon – Centre
5. Associação de Cuidados de Saúde da Portugal Telecom – Lisbon – Centre
6. Hospital de Águeda – Agueda Centre/North
7. Portuguese Institute of Oncology – Coimbra – Centre/North
8. Paediatric Unit of the Portuguese Institute of Oncology – Porto - North
9. Haemato-oncology Unit of the Portuguese Institute of Oncology – Porto – North
10. Hospital Pedro Hispano – Porto – North

For the control group, only participants who did not work in palliative care were invited to participate and the reason for this will be explained below. Permission was received from the ethical committee of the Portuguese Institute of Oncology from Porto to invite HCWs from their surgical units.

3.4 SAMPLE

3.4.1 CALCULATION OF THE NUMBER OF PARTICIPANTS REQUIRED FOR THE INTERVENTION GROUP

According to the official statistics of the Portuguese Nursing Society for 2006, the total amount of nurses caring for patients in Portugal was 32 800 (Ordem dos Enfermeiros, 2011) and according to the Portuguese Health Ministry, the total amount of nursing aides in 2008 was 27407, which totals 60207. Other professions were not considered, as they were a minority in this study. Estimating that approximately 20% of these HCWs worked specifically with patients with a terminal condition, this reduced the total amount to 12041. The minimum sample size necessary to represent this population was then calculated. As a result of observing problems in published manuscripts, Bartlett et al. (2001) presented a formula based on Cochran's sample size formula for determining sample size for both continuous and categorical data (Cochran, 1977). The first step was to estimate the variance of the variables, which in this study, was scaled. This was done by determining the inclusive range of the scale, divided by the number of standard deviations that would include all possible values in the range, and then square this number. The questionnaires in this study have a scale from 1 to 6 and given that six standard deviations (three to each side of the mean) would capture 98% of all responses, the calculations would be as follows:

$$S = \frac{6 \text{ (number of points on the scale)}}{6 \text{ (number of standard deviations)}} = 1$$

Where S = the estimated standard deviation of 98% of the population. Having calculated this, Cochran's sample size formula for continuous data is as follows: (Bartlett, et al., 2001, p. 46):

$$n0 = \frac{(t)2 * (S)2}{(d)2} = \frac{(1.96)2 * (1)2}{(6*.03)2} = \frac{3.84 * 1}{0.0324} = 118{,}5$$

Where n0 = recommended sample size

Where t = value for selected alpha level of .025 in each tail = 1.96 (the alpha level of .05 indicates the level of risk the researcher is willing to take that true margin of error may exceed the acceptable margin of error).

Where S = estimate of standard deviation in the population = 1. (Estimate of variance deviation for 6 point scale calculated by using 6 [inclusive range of scale] divided by 6 [number of standard deviations that include almost all (approximately 98%) of the possible values in the range]).

Where d = acceptable margin of error for mean being estimated = .18 (number of points on primary scale * acceptable margin of error; points on primary scale = 6; acceptable margin of error = .03 [error researcher is willing to accept]).

However, Cochran (1977) also argued that if this result exceeded 5% of the population, then a further correction formula would need to be applied. In our study, assuming that the total population of HCWs who cared for patients with a terminal condition was 12041, then 5% of this would be 602, which was not exceeded by 118,5. We could therefore assume that a minimum sample necessary to obtain significant results was 119 participants (118.5 taken to the next decimal).

The inclusion criteria were HCWs who worked full time with patients with a terminal condition and who were prepared to participate in the research by filling in pre and post intervention questionnaires and participate in the intervention. The exclusion criteria were HCWs who did not wish to participate in the intervention.

In summary, from the HCWs approached, the aim was to obtain a minimum of 120 HCWs for the Intervention group.

3.4.2 CALCULATION OF THE NUMBER OF PARTICIPANTS REQUIRED FOR THE CONTROL GROUP

A control group should contain approximately the same amount of participants as the experimental group and be comprised of participants with similar characteristics (Greene, 1990). In this study, due to the scarcity of palliative care units in Portugal in relation to routine end of life care, it was not considered possible to obtain the same amount of HCWs as the intervention group and simultaneously maintain the same ratio between HCWs who work in and out of palliative care. For this reason, a control group was only used for HCWs who cared for patients with a terminal conditionpatients with a terminal condition out of palliative care units and the aim was to obtain similar numbers. Therefore, considering that the intervention group consisted of 120 participants and that half of these were HCWs who cared for patients with a terminal condition out of palliative care units, the intention was to achieve 60 HCWs.

As these HCWs would not be given the opportunity to receive the intervention , permission was required from the ethical commission of the institutions they worked at. Permission was received from the Ethical Commission of the Portuguese Institute for Oncology in Oporto, where a large amount of interventions had been carried out, to distribute the questionnaires among the HCWs of their surgical units.

Inclusion criteria were HCWs who worked full time with patients with a terminal condition and agreed to participate in the control group by filling in the questionnaires with a 4 month interval. The exclusion criteria for the control group were any HCWs who had previously been part of the intervention group and then subsequently changed to the surgical unit or did not wish to participate.

In hindsight, there is a need to acknowledge, that although the control group was similar to the experimental group in that both cared for patients with a terminal condition out of palliative care units, it is possible that there may have been some difference in their state of mind, because the surgical unit receives many patients early in their disease, who are often able to return home. However, since this was the group authorized by the ethical committee of the hospital, this limitation was accepted. As mentioned previously, baseline studies will also be performed to better understand the pre-existing differences between the two groups.

3.4.3 SAMPLING FOR INTERVIEWS

Each institution that participated in the intervention group was approached with the aim to recruit participants for an interview. According to Marshall (1996), this can be considered purposive sampling and more specifically, ‘Critical Case Sampling’, because participants with specific experiences will be chosen (those having participated in the intervention).

The aim was to obtain a sufficient number of participants to increase the likelihood of hearing most or all of the perceptions that might be important. According to Marshall (1996), ‘an appropriate sample size for a qualitative study is one that adequately answers the research question’. This can be understood by the researcher, when new themes cease to emerge (data saturation). There are however, diverging opinions regarding this matter. Studies differ on what is an adequate sample in order to achieve data saturation. Creswell (1998) suggest 20 to 30 participants for grounded theory methodology and 5 to 25 for phenomenology. Morse (1994) suggest 30 to 50 interviews for ethnography and ethno science, at least 6 for phenomenology and 30 to 50 interviews for grounded theory. Without specifying what type of qualitative study, Charmaz (2006) suggest 25 participants for smaller projects, Ritchie et al. (2003) found that qualitative samples often ‘lie under 50’ , whilst Green & Thorogood (2004) claim that most qualitative researchers find that little new information emerges from interviews after more or less 20 interviews. A study performed by Mason (2010) analysed 560 PhD studies and found that the mean sample size for interviews was 31. Chenitz & Swanson (1986) also suggest that 30 interviews are sufficient to achieve data saturation.

Considering the above mentioned studies, a sample of 30 participants for the interviews was considered adequate to achieve data saturation.

3.4.4 SUMMARY

In summary, by inviting all the institutions mentioned in section 2 (Sites), an estimate of 890 HCWs would have the opportunity to participate in the research if all accepted and they would be distributed as follows:

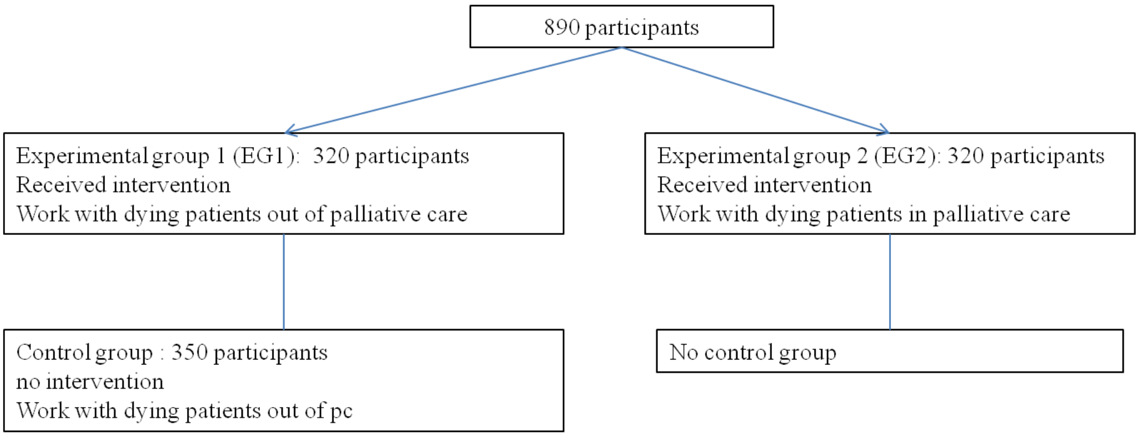


FIGURE 10 - SAMPLE INVITED TO PARTICIPATE IN THE STUDY

Although the above calculations show that not such a large amount of participants were necessary, they were invited to ensure that the final sample would be sufficient. It was not expected that all institutions invited would accept.

Of these, a minimum of 120 participants would be needed for the intervention group to obtain significant results, with 60 participants in each experimental group. As the control group should be similar in number and characteristics as the experimental group, the aim was to obtain 60 participants for EG1. Of the 120 participants in the intervention group, the aim was to interview 30.

3.5 RECRUITMENT METHOD AND ACCESS TO PARTICIPANTS

3.5.1 INTERVENTION GROUP

The directors of Portuguese health care institutions who cared for patients with a terminal condition were approached by the training department of the Association AMARA- Associação pela Dignidade na Vida e na Morte with a proposal to participate in a research project for psycho-existential-spiritual training for HCWs who care for patients with a terminal conditionpatients with a terminal condition, funded by the Calouste Gulbenkian Foundation in Portugal. A full explanation sheet of the research was provided (see appendix nº 17). The training was accepted by HCWs of 4 palliative care units (2 in Lisbon and 2 in Oporto) and 4 units who care for patients with a terminal condition (one haemato-oncology unit in Oporto, one continuing care unit in the Algarve, a group of health care workers from different hospital units in the Alentejo who were being recruited to participate in a project for palliative care at home, and one old people's home in Lisbon with a unit for patients with a terminal condition). Although the common denominator was patients with a terminal condition, the study covered different types of units (hospital, nursing home and community care) and different parts of the country (south, centre and north), thereby ensuring geographical and institutional diversity.

Once the units had accepted to participate in the study, a meeting was held with the clinical director and the head nurse of each unit to explain the study in more detail and subsequently, the study was explained to the HCWs by the clinical director or the head nurse and a note was made by the head nurse of who wished to participate. Bias was minimised as the clinical directors or head nurses opened participation to all in a wide information call and entry to the course was not limited; there were vacancies for all who wished to participate.

As permitted by the quasi-experimental design, the selection method was one of self-selection (Shadish, et al., 2001), for the intervention group: as previously mentioned, the HCWs were free to either participate in the intervention or not — thus, they were not randomly chosen.

3.5.2 CONTROL GROUP

After being given authorization from the Ethical Committee of the Portuguese Cancer Institute (Appendix 16), the head nurses from surgical oncology wards were approached to involve their personnel in a control group. The head nurses of each surgical unit were in charge of distributing the questionnaires and identification sheets on two occasions with an interval of four months (appendix 6 and 2) and a sheet explaining the research to all the HCWs (Appendix 3 and 4). Participation was not compulsory.

3.5.3 INTERVIEWS

Four months after the interventions, the head nurse of each institution was contacted to recruit HCWs who had participated in the intervention and who would be willing to carry out an interview. The aim was to obtain approximately 4 HCWs from each institution, which would add up to 32 HCWs.

3.6 INSTRUMENTS

Three questionnaires were used to assess the effect of the training with regard to burnout, the helping relationship with the patient and family and personal well-being. The questionnaire to assess burnout is based mainly on the Maslach Burnout Inventory (Maslach, et al., 1986), which is a well known questionnaire used world-wide. The Barrett-Lennard Inventory (Barrett-Lennard, 1964), (Barrett-Lennard, 1978) to assess the quality of the helping relationship is a well-known instrument within the Person Centred Approach and the Well-Being questionnaire was devised by the author. These were distributed to the participants one week before the intervention with a letter of presentation and an identification sheet (Appendix 5 and 6), and redistributed four months later with another identification sheet (appendix 7).

3.6.1 QUESTIONNAIRE TO ASSESS LEVEL OF BURNOUT

(Appendix 8)

Description

The questionnaire on burnout was devised by the researcher (CGM) to measure emotional exhaustion, depersonalization, and personal fulfilment specifically in HCWs who care for patients with a terminal condition, as opposed to HCWs in general. The items were devised using several methods. Most of the items were adopted from past validated questionnaires, in this case, the Maslach Burnout Inventory (Maslach, et al., 1986) which assessed emotional exhaustion (EE), depersonalization (D) and professional fulfilment (PF) and the Burn-out Test (Service Fields) by Jerabek (2001), which assessed detachment (D) and job fulfilment (PF). According to Streiner and Norman (2008), this is common practice, because it saves the work of constructing new questions; because they have already gone through repeated processes of psychometric testing and because there is only a limited number of ways to ask about a specific problem. The remaining items were devised specifically by the author.

Following is an explanation of the origin of the items:

The Maslach Burnout Inventory.

Authorization was received from the Maslach Burnout Inventory (MBI) authors to translate questions from the MBI and to integrate them into the questionnaire; (see appendix 9)

EE 1	I feel emotionally drained by my work.
EE 20	I have no strength left at the end of a day's work.
EE 6	I feel tired when I get up in the morning and have to face another day of work
EE 8	I feel frustrated by my work
EE 23	I feel that I work too hard in my profession
EE 31	Working directly with people causes me a lot of stress
EE 15	I feel worn out
EE 18	Working every day with people is a real burden for me
D 2	I feel that I treat many people impersonally, as if they were objects
D 7	I have become more insensitive to people since I have this job
D 12	I am afraid this job will make me become emotionally hard
D 16	I do not pay real attention to what happens to other people
D 37	I feel that other people censor me because of their own problems
PF 3	I resolve other people's problems efficiently
PF 5	I can easily understand what other people are experiencing
PF 32	I have a positive influence on the people I coordinate at work
PF 36	I feel energetic
PF 14	It is easy for me to create a relaxed atmosphere with other people
PF 17	I feel fulfilled when I work in close collaboration with others
PF 19	I have accomplished many useful things in this work
PF 26	At work, I deal with emotional problems very calmly

EE = EMOTIONAL EXHAUSTION; D = DEPERSONALIZATION; PF = PROFESSIONAL FULFILLMENT

TABLE 1 - QUESTIONS INTEGRATED FROM THE MBI

Psychtests aim Inc (Jerabek, 2001)

Authorization was received from PsychTest Aim Inc. authors to translate the questions and to integrate them into the questionnaire; (see appendix 10)

D 4	I would be incapable of coping with my work if I considered my patients as unique individuals
D 24	I don't really care what happens to my patients
D 27	I cannot afford to answer to the individual needs of my patients.
PF 22	I feel that what I do makes a difference
PF 29	I feel that other people have realistic expectations regarding my working performance

TABLE 2 - QUESTIONS INTEGRATED FROM PSYCHTEST AIM INC

Questions devised by the writer specifically for burnout related to working with patients with a terminal condition

Several methods were used to devise the questions specifically related to burnout in end of life care:

Research: Causes for burnout in end of life care described in the literature review contributed towards an understanding of what type of questions to ask.

Expert opinion: a survey was performed with nurses who worked with patients with a terminal condition, to understand what their difficulties were (see appendix 11). This confirmed the findings of the literature review, but also provided adequate terms and statements to use. 14 items were devised, as follows:

EE21	Dealing psychologically with terminally ill patients makes me feel insecure and anxious
EE 10	I feel helpless when faced with the patient's fragility
EE 25	I am emotionally disturbed by the death of so many patients
EE 28	The relationship with the patient's family wears me out
EE 13	I am frustrated because I cannot find the time to have a quality relationship with the patient
EE 35	I feel stressed due to lack of debate and support within the team, with regard to our difficulties
EE 38	I ask myself many times if I could have "done more" and this makes me feel anxious

D 30	I give more importance to the technical part of my work than to the human part
D 34	I give a lot of importance to treating the illness, but do not have patience for the psychological and spiritual caring of the patient
PF 9	I feel fulfilled at work because I manage to find time to just "be" with the patient or their family
PF 33	I have moments of sharing with the patients, with no need to hide my feelings
PF 11	My work allows me to value life more
PF 39	I manage to find time in my work to talk to patients and to help them find meaning in their lives
PF 40	I often contribute towards giving my patients quality of life, comfort and dignity at the end of their life

TABLE 3 - QUESTIONS DEVISED BY CGM

3.6.2 BARRETT-LENNARD RELATIONSHIP INVENTORY TO ASSESS THE QUALITY OF A HELPING RELATIONSHIP

(Appendix 12)

Description

This questionnaire was constructed by Barrett-Lennard, from the "Centre for Studies in Human Relations" in Perth, Australia. The first version is from 1964 (Barrett-Lennard, 1964) and was successively changed until 1978 (Barrett-Lennard, 1978). It was developed for academic and therapeutic purposes. There is an inventory of 40 questions and another of 64, each with two versions: "other towards self" and "myself to the other". This research used the 40 questions "myself to the other" version. Some items were substituted with items from the 64 question inventory because they seemed more appropriate for HCWs. The inventory was translated into Portuguese by the author in 2002 for a research study (Gouveia e Melo, 2003) and revised by Prof. Doutor J. Hipólito (Hipólito, .2012). Authorization from Professor Barrett-Lennard was obtained for these changes (see appendix 13).

Items from this questionnaire were based on the necessary and sufficient attitudes in Client Centred Therapy by Carl Rogers (Rogers, 1951): Positive regard (PR), Empathy (E), Unconditional acceptance (UA) and Congruence (C), with positive and negative questions:

Positive questions

PR 1	I respect them as people
PR 5	I like them
PR 13	I appreciate and value them as people

PR 21	I care for them
PR 29	I feel friendly and warm towards them
E 2	I usually sense or realize how they are feeling
E 10	I nearly always see exactly what they mean
E 18	I can tell what they mean, even when they have difficulty saying it
E 26	I usually can tune in and understand all of their meaning
E 34	I appreciate just how their experiences feel to them
UA 7	Whether they are feeling happy or unhappy with themselves doesn't make me feel more or less positive towards them
UA 15	My liking or disliking of them isn't changed by anything they say about themselves
UA 27	Whether they are expressing 'good' thoughts and feelings, or 'bad' ones, does not affect the way I feel towards them
UA 31	The way I feel about them doesn't depend on their feelings towards me. (taken from the inventory of 64 questions)
UA 39	I don't think that particular things they say or do alter the way I feel towards them
C 8	I don't avoid or put off dealing with anything that matters between us
C 12	I feel that I am genuinely myself with them
C 20	I am willing to say whatever is in my mind with them, including feelings that come up in me about either one of us, or how I see us getting along
C 24	I am able to be openly myself in our relationship
C 32	I know exactly what I feel in relation to them. I don't sense anything that's hard to face and admit to myself

TABLE 4 - POSITIVE ITEMS OF THE BLI

Negative questions

PR 9	I feel indifferent to them
PR 17	I find them rather dull and uninteresting
PR 25	I do feel disapproval of them
PR 33	I put up with them (taken from the inventory of 64 questions)

PR 37	I do feel impatient with them (taken from the inventory of 64 questions)
E 6	I hear their words, but don't know how they feel inside
E 14	At the time, I don't realize how touchy or sensitive they are about some of the things we discuss. (taken from inventory of 64 questions)
E 22	I screen out and don't pick up on some of their feelings
E 30	I really don't understand them
E 38	I respond to them rather automatically, not always taking in what they are experiencing
UA 3	The interest I feel in them depends on their words and actions
UA 11	Depending on their actions, I have a better opinion of them sometimes than I do at other times
UA 19	I would like them to be a particular kind of person
UA 23	If they get impatient or mad at me, I become angry or upset too. (taken from the inventory of 64 questions)
UA 35	Sometimes they seem to me a more worthwhile person than they do at other times
C 4	I tend to put on a role or front with them
C 16	I don't show my inner impressions and feelings with them
C 28	Sometimes I am not at all comfortable with them, but we go on, outwardly ignoring it
C 36	There are times when my outward response to them is quite different from the way I feel underneath
C 40	It bothers me when they try to ask or talk about certain things (taken from the inventory of 64 questions)

PR = POSITIVE REGARD; E= EMPATHY, UA= UNCONDITIONAL ACCEPTANCE; C= CONGRUENCE

TABLE 5 - NEGATIVE QUESTIONS OF THE BLI

3.6.3 QUESTIONNAIRE TO ASSESS LEVEL OF PERSONAL WELL-BEING

(Appendix14)

Description

This questionnaire was developed by the author, based on the fears of life and death, which were approached in the intervention. Several methods were used to devise the questions:

Research: Causes for death anxiety in end of life care described in the literature review contributed towards an understanding of the main dimensions to focus on: Fear of loneliness, separation and abandonment in relation to loved ones (FLS), fear of the unknown (FU), fear of being judged and losing dignity (FJD), fear of not having meaning in life (FM), fear of physical pain (FP).

Clinical observation: Before the start of this study, the intervention was given regularly in Portugal since 2003, to volunteers who wished to accompany patients with a terminal condition, many of which were HCWs. Observation and note taking of comments made by HCWs who care for patients with a terminal condition in these interventions provided the material needed to devise statements based on reality. These observations were in agreement with the findings of the literature review.

The following 50 items were devised containing positive and negative questions of the above mentioned dimensions. The negative questions express the opposite trait of the dimension. For example: 'I am not at ease until I have everything "under control"' as opposed to 'I normally accept what I cannot change', or 'I often think about my relationships to see if there is any unfinished business with anyone' as opposed to 'I normally feel resentment towards others without trying to find a solution'.

Positive questions

FLS 1	I have many real friends whom I can count on
FLS 11	I often think about my relationships to see if there is any unfinished business with anyone
FLS 21	I make a point of finding time in my life to be with friends.
FLS 31	I normally phone friends and family, just to see how they are.
FLS 41	I normally tell people I love, what they mean to me
FLS 2	I face challenges with quite a lot of internal confidence
FLS 12	I feel I have strategies and inner strength to deal with unforeseen situations that appear in my life
FU 22	I normally accept what I cannot change
FU 32	I accept difficult situations as part of my life journey and personal growth
FU 42	I feel that I have external resources to overcome the more complicated moments of my life
FJD 3	Apart from my physical aspect, I also value the emotional and spiritual side of me
FJD 13	My dignity does not depend just on my usefulness in society

FJD 23	I can accept aging and the gradual degradation of my body as a natural stage in life
FJD 33	I feel the same person, even when I am not happy with my physical appearance
FJD 43	My body is not perfect, but I like it all the same
FM 5	I feel fulfilled in my profession
FM 15	Right now, I think that my life has meaning
FM 25	I find ways to feel fulfilled in every-day life
FM 35	If I only had a short while to live, I think I would continue to do more or less what I am doing today
FM 45	If I only had one more year to live, there would not be many things I would stop doing because they are a waste of time
FP 9	Deep down, I know that I can tolerate more physical pain than I think
FP 19	I know that physical weaknesses will not stop me from continuing to contribute towards giving meaning to my life
FP 29	I accept that physical pain, like any other, is part of life, whether it is my pain or other people's pain
FP 39	In spite of the physical pain that I may suffer from, life will continue to have meaning
FP 49	I trust that when the time comes, I will receive what I need to deal with my physical pain.

FLS = FEAR OF LONELINESS, SEPARATION AND ABANDONMENT IN RELATION TO LOVED ONES;
FU = FEAR OF THE UNKNOWN; FJD = FEAR OF BEING JUDGED AND LOOSING DIGNITY;
FM = FEAR OF NOT HAVING MEANING IN LIFE; FP = FEAR OF PHYSICAL PAIN.

TABLE 6 - POSITIVE ITEMS OF PERSONAL WELL-BEING

Negative questions

FLS 6	If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them
FLS 16	With regard to my relationships, I normally put a stone on matters that disturb me
FLS 26	I often do not show my appreciation to friends and family, and then regret it
FLS 36	I normally feel resentment towards others without trying to find a solution
FLS 46	I am always in a hurry and do not always notice or thank the caring gestures of other people

FU 7	I normally feel quite unconfident when faced with the unknown
FU 17	I am not at ease until I have everything “under control”
FU 27	I feel the need to be informed of everything that surrounds me
FU 37	I do not feel capable of dealing with big changes in the “status quo” of my life
FU 47	I do everything I can to avoid any difficulties or instabilities in my life
FJD 8	I cannot feel that I am of value if I do not have a good physical appearance
FJD 18	If I cannot be an active and independent person, my life would lose all meaning
FJD 28	If I become ill, I would rather die than become dependent on others
FJD 38	I am afraid of being a burden to others
FJD 48	Physical degradation frightens me. It makes me feel reduced to nothing
FM 10	I spend a lot of time doing activities I do not like
FM 20	There is no balance in my life between obligations and leisure
FM 30	I still need to identify what I still want to do in life before dying
FM 40	I spend a lot of time trying to give well-being to others, with damage to my own well-being
FM 50	I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life
FP 4	If I have to die, may it be quick
FP 14	Without physical health, it is not worth living
FP 24	The time of dying has no value. It is best to die quickly to end the suffering
FP 34	I would rather die than be in physical pain
FP 44	I cannot conceive living with a big physical disability

TABLE 7 - NEGATIVE ITEMS OF PERSONAL WELL-BEING

These dimensions and positive and negative items were then intercalated and equally distributed to form the final version of the questionnaire.

3.6.4 VALIDATION AND RELIABILITY OF THE QUESTIONNAIRES

Apart from the questionnaire on existential well-being, which was developed and validated specifically for this research, the previous sections describe the questionnaires as they were originally designed and validated by their authors. However, it was considered important to submit all three questionnaires to new validation tests to obtain certainty that they were in fact measuring what they were originally designed to. Although a questionnaire may be designed logically, following theoretical studies, and submitted to validation tests, it is not possible to foresee all the characteristics of a different sample to be certain that they will all perceive and interpret the questions in the same way. For example, the MBI was originally validated in America, and the Barrett-Lennard Inventory in Australia, but the sample of this research was composed of Portuguese nurses who come from a different culture and their nursing training may also be different, for example focusing more on the technical and medical aspects of nursing compared to the human side or vice versa. Also, within the nursing profession, these nurses come from a specialized area – death and dying - which may cause them to differ even more from other populations. The following paragraph will explain how this can affect the interpretation of the questionnaires.

Questionnaires are designed with groups of questions that measure one dimension. For example, the Barrett-Lennard Inventory measured four different aspects of helping relationship attitudes: positive regard, empathy, unconditional acceptance and congruence. By performing principal component analyses (PCAn), it is possible to certify that these participants are perceiving these four dimensions as separate groups, and if not, they will be regrouped according to the results of the PCAn, and renamed by the researcher, who will look at how the items have been grouped, to make sense of them. Possible outcomes are that two dimensions are collapsed into one, or on the contrary, the dimensions may become smaller and more numerous. It is also possible that PCAn can result in separating positive and negative questions in separate dimensions. Only once this has been done, can the items be correctly summed as dimensions, to prepare for statistical analysis. These validation tests are an important part of the research, as all the quantitative results are based upon the results of these analyses. The following paragraphs will describe the methodology of these validation analyses.

The initial questionnaires were submitted to a pilot test with 10 participants who were debriefed to ensure that all questions were understood as intended. Ethical consent of the clinical director of each hospital department was obtained to distribute the questionnaires to the HCWs who agreed to participate in a research project to understand if an intervention comprising of education together with personal introspection relating to death anxiety could reduce burnout and improve the quality of care and relationship with patients and their families.

The questionnaires were filled in by HCWs who had not yet received the intervention. They were each given a cover letter explaining the research project and an identification sheet with demographic data (age, sex, place of work - in or out of a palliative care unit, - level of education, profession and marital status). Anonymity was assured. The questionnaires were collected for sensitivity tests, construct, convergent and divergent validation and tests of internal consistency.

Four months later, the questionnaires were distributed again to the participants who had completed the intervention and test-retest reliability analyses were performed.

The validation of the questionnaires used in this study was performed using the questionnaires from both the intervention and the control group.

The literature shows conflicting opinions on how many participants are needed to validate a questionnaire. Nunnally (1978) has suggested 10 participants for each variable. Kass and Tinsley (1979) recommend between 5 and 10 participants up to a total of 300 participants, at which point they consider test parameters to be stable regardless of the ratio between the number of participants and the number of variables. The view that 300 participants are sufficient has been supported by other researchers (Tabachnick & Fidell, 1996; Comrey & Lee, 1992) and the latter also add that 300 is a good sample size, 100 is poor and 1000 is excellent. Finally, a study by Arrindell & van der Ende (1985) concluded that changes in the ratio made little difference to the stability of factor analysis. This shows that there is not a clear consensus on the actual number needed for adequate validation.

However, the ratio of participants to variables has not been the only criteria to effectively perform factor analysis. A study by Guadagnoli and Velicer (1988) considered the absolute magnitude of factor loadings to be more important. They suggest that 4 or more loadings greater than 0.6 is reliable regardless of the size of the sample or 10 or more loadings greater than 0.4 is reliable if the sample is greater than 150. However, the drawback of this system is that one needs to perform the validation studies in order to decide whether the sample is adequate.

Based on this information, and considering that the largest questionnaire in this study has 50 items, the aim was to obtain 300 participants, and if this was not possible, a minimum of 250 participants, to fulfil the criteria of a minimum of 5 participants per item. The aim was also to obtain an equal amount of HCWs who worked in palliative care units and those who cared for patients with a terminal condition out of palliative care units and to include all professional categories that participated in the care of the patient, such as doctors, nurses, nursing aides, psychologists, chaplains, physiotherapists and occupational therapists, in proportionate numbers in relation to the constitution of the team. After the completion of the validation tests, the factor loadings would be analyzed for confirmation.

Tests for sensitivity of the individual items, construct, convergent and divergent validation and tests-retest analyses were performed for each questionnaire. Full results of these tests and details of the sample can be found in appendix 15.

3.6.5 QUALITATIVE QUESTIONS WHICH WERE INCLUDED IN THE SECOND QUESTIONNAIRE

Following the 3 quantitative questionnaires, the participants were also asked to answer questions in their own words. The questions were designed to understand the main impact of the training on the participants (questions 1 and 2), to evaluate the structure and teaching methods (question 3), how it affected their relationship with the patient and family and also how it affected their own well-being (question 4), and finally, how it could be improved (question 5). Questions 6 and 7 were asked because there was the possibility at the time to provide further training for these participants after the end of the research. Question 8 was to give them the liberty to raise any other subject they thought relevant. The questions were as follows:

1. What was the most important thing you learnt in the training?
2. What was the main help you received from this training?
3. What did you appreciate (or not) in this training, in terms of content, structure, teaching methods, liberty to express feelings etc...) ?
4. In what way did the training improve, or not, the following (please specify):
    a. Your relationship with the patient?
    b. Your relationship with the family?
    c. Your relationship with work colleagues?
    d. Your efficiency at work?
    e. Your self-knowledge?
    f. Your internal congruence?
    g. Your daily life and feelings of well-being?
5. In your opinion, how could this training be improved?
6. In your opinion, would follow-up workshops be beneficial? If so, what kind of workshops would you like?
    a. Difficulties in communicating with patient and family?
    b. Difficulties in communicating with the team?
    c. Spiritual care?
    d. Health care worker's emotional relationship with the "body" of the patient (smells, different types of touch, looks, "symbolic contamination" etc?
    e. The meaning of my life?
    f. Open theme group encounters?
7. Any other theme you would like to mention?
8. Any additional comment you would like to add (optional)?

3.6.6 INTERVIEW SCHEDULE FOR LIVE INTERVIEWS

The interviews were carried out in a semi-structured fashion (Pope & Mays, 2006) with the following questions in mind:

A few months ago, you did the AMARA training course. I would like to know what impact the course had on you. Did you notice any change, positive, or negative, after the course?
1. In terms of you as a person and your private life
2. In terms of your professional life:
a. With work colleagues
b. With the patients and family

3. Is there anything you would like to say about the course itself
a. In what way was the course useful
b. Was there anything you were unhappy about
c. Do you have any suggestions
4. Any comments you would like to add

TABLE 8 - INTERVIEW SCHEDULE FOR LIVE INTERVIEWS

The questions were designed to evaluate how the intervention impacted on the personal well-being of HCWs, their relationship at work with colleagues and their helping relationship with family and friends. Questions were also asked to evaluate the intervention itself and how it could be improved and finally, the interview schedule ended on an open note, giving them the liberty to add anything they wished to.

Although these questions were similar to the qualitative questions from the second questionnaire it was considered a necessary precaution in order to obtain correct and complete feedback. Filling in questionnaires can be cumbersome, and there is a risk that participants may not give complete feedback. This risk is minimised in a live interview. A live interview also gives the attentive interviewer the possibility to pick up on issues that may otherwise have been missed.

3.7 ASSESSMENT PROCEDURES AND DATA COLLECTION

Before the training, participants were given a letter explaining the research project (Appendix 5) and were asked to fill in the 3 questionnaires and an identification sheet with demographic details (Appendix 6), to assess their level of personal well-being (Appendix 14), burnout (Appendix 8), and the quality of their helping relationship (Appendix 12). These questionnaires were returned at the beginning of the first day of the intervention (T1) and verified for missing data. Only after collection of the questionnaires was the intervention started. Four months after the training, the participants were asked to fill in the same questionnaire to assess how they felt now (T2), as well as how their perception was today, of how they were before the training (T1p), and they were also asked to answer some qualitative questions for content analysis (section 6.5). The questionnaires were recollected by the head nurse of each department, who had a list of the HCWs who had participated in the intervention. However, as many questionnaires from the second batch of questionnaires four months after the intervention were received with considerable delay, the participants of the last interventions were given a consent form at the beginning of the intervention, accepting a commitment to fill in both questionnaires (appendix 19).

A letter of presentation (Appendix 3) and the same questionnaires were also given to the control group and again after 4 months with another accompanying letter (Appendix 4). The second group of questionnaires did not contain the qualitative questions that were given to the intervention group. The head nurses of the units assumed the responsibility of distributing the questionnaires to all HCWs in the unit and recollecting them.

At the beginning of the intervention, participants were asked what their difficulties were in caring for the dying, and their answers were written on the board by the facilitator and subsequently registered in a notebook. It is important to state that although some comments were only mentioned once or twice, they are important and a reflection of what the HCWs felt in general, because they were repeatedly brought up verbally during the trainings. Unfortunately, because the intervention was given in a therapeutic atmosphere and the facilitator was doing group therapy, a written record of everything that was said during the interventions was not made, although notes were made after the intervention. Copies were only kept of certain exercises to help the HCWs reflect on themselves, where the facilitator took notes to give back to them, such as their coping methods and their personal resources to cope with life obstacles etc. On the other hand, whether important or not, the reality is, that participants did chose to mention several issues repeatedly in the written feedback, and not others and therefore, this does need to be taken into account.

After data collection, and as mentioned previously, baseline studies were performed on the quantitative data for reasons mentioned by Grimshaw (2000) who argues that because of the differences between the experimental and control group, performance at baseline may differ, compromising the internal validity of the results. These baseline studies were performed on the 280 participants used in the validation of the questionnaires. The results were then compared with the individual results of the experimental and control group to ensure there were no significant differences in the pre-test results.

After the second questionnaire, live semi-structured interviews which varied from 20 to 30 minutes each were carried out with the participants who had agreed to be interviewed at their work place, in a private room, during working hours and by qualified counsellors. The interview schedule consisted of questions surrounding impact on personal life, professional life and comments on the training itself. These interviews were recorded and subsequently transcribed.

3.8 DATA ANALYSIS

3.8.1 STATISTICAL ANALYSIS OF QUANTITATIVE DATA

Statistical analysis for all the quantitative data was performed using SPSS 16 (Pallant, 2007) because this statistical analysis package is well suited to the social sciences and is widely used. All three questionnaires used continuous scores, from 1 to 6 in order to facilitate comparison between questionnaires. An even number was chosen to oblige the participant to choose rather than simply ticking the middle score without much reflection. According to Streiner and Norman (2008) there is no set rule on whether to use odd or even category numbers and this can be left to the needs of the researcher. The score for each factor was then summed and divided by the number of items in the factor.

Due to the high number of participants, parametric tests were used, although the distribution was not always normal. Pearson's correlations were used to assess relationships between factors. Paired samples t-tests were used to compare the general summed scores of participants before (T1) and after the course (T2), and perception today (4 months after training) of how they were before training (T1p) and independent-samples t-tests and one-way between-groups analysis of variance (ANOVA) were used to compare the scores before and after the course of different groups of HCWs (their differences determined based on two age groups, whether or not they worked in palliative care units, and their specific professions). All tests were two-tailed and alpha value was set at 0.05.

Cut-off point was calculated as the mean of the 11 factors of the 3 questionnaires, separating positive and negative factors, i.e. we calculated the mean of the negative factor and the mean of the positive factors. We then summed up these two figures and divided by two. See following table for a clearer understanding:

Positive factors	Mean	Negative Factors	Mean
Empathy and congruence	4.27	Avoidance mechanisms	2.93
Unconditional acceptance	5	Distance and impatience towards patient	1.87
Self-confidence, dignity and meaning in spite of adversity and	4.46	Fear of dependence, physical degradation and loss of control	3.8
Close relationships and personal well-being	4.74	Self criticism regarding no time for family, friends and meaningful activities	3.21
Professional fulfilment	4.44	Emotional exhaustion	3.1
		Depersonalization	1.81
Total	22.91		16.72
Mean	4.58		2.79
Cut-off point = mean of positive and negative factors:		(4.48+2.79)/2	3.69

TABLE 9 - CALCULATION OF CUT-OFF POINT

3.8.2 ANALYSIS OF QUALITATIVE DATA

Schilling (2006) suggests that when transcribing interviews in preparation for content analysis, the researcher needs to decide whether all the questions of the interviewer or only the main questions from the interview guide be transcribed; whether the verbalizations be transcribed literally or only in a summary; and whether observations during the interview (e.g., sounds, pauses, and other audible behaviours) should be transcribed or not. In this study, each interview was recorded and transcribed verbatim, however sounds, pauses and other audible behaviours were not transcribed, unless considered relevant. The interviews were transcribed consecutively. The written questions were transcribed and inserted into Microsoft Access so that they could be consulted either by participant or by question. The data was also imported and stored into the NVivo application. All documents were kept securely in the researcher's computer, which is password protected. The original handwritten questionnaires were kept together with the quantitative questionnaires. One interview was translated and analysed. A copy of this interview, the thematic framework (NVivo node structure) and the results of the analysis of this interview can be found in appendix 28.

Nvivo 8 (QSR International, 2007) was used to perform content analysis in the form of thematic analysis (Pope, 2006) on the qualitative data (interviews and written answers to questions). The main categories were pre-defined following the qualitative questions and the interview grid, and their sub categories were created by the author as the text was being analysed. Each relevant sentence was highlighted and dragged to an already existing category or to a new one created at the time. Categories were then re grouped into themes. Once all the text had been analysed and categories created, all the data was reanalysed to check that no relevant quotations are overlooked. Once finished, Nivo8 has tools allowing for reports, charts, queries, and modelling. In this case, reports were used to count the number of references allocated to each category and modelling was used to interpret and organise the categories into meaningful groups, using geometrical shapes and colours. The selected categories are all pasted onto the screen and can be moved around and coloured by the author to make sense. For further illustration, examples of quotes from each category were given.

Several reasons were considered for using qualitative data anlaysis software over manual coding. The program provides a single location for all materials to be stored and has the ability to store large amounts of materials with consistent coding schemes (Weitzman, 2000) (Sin, 2007) (Bergin, 2011). Quotations can be allocated to virtual categories and sub-categories and can be changed, merged or renamed easily without the need to reprint interview transcripts (Odena, 2013). Software packages may also save time managing data and provide easier means to ensure that no relevant quotations are overlooked (Odena, 2013). Webb & Vulliamy (2007) argued that another important advantage when using software is that when retrieving all coded text within a category, any unconscious bias by the researcher as to the relative importance of the category is revealed. Furthermore, Bazeley (2002) raised advantages beyond the technical integration and ease of data management, arguing that software allows for higher levels of analytic integration of qualitative and quantitative data sources, thereby ensuring more robust findings.

However, despite these advantages, there is still some reticence among social scientists regarding the use of qualitative data analysis software such as the fear that the software may 'drive' the analysis (Crowley, et al., 2002), or that computers can distinguish the relevant information form data-sets and develop the ideas in order to meet the research project's requirements (Gahan & Hannibal, 1998), (Lu & Shulman, 2008), However, Gibbs (2004) argues that "it is not the computer that interprets the text, but the person". Odena (2013) also suggests that it is the researchers who are in charge of building up the analysis, having the ideas, engaging with the data and making all the decisions about the study.

3.8.3 ASSESSING THE WORTH OF QUALITATIVE DATA

The trustworthiness (Streubert & Carpenter, 1999) of the data was assessed in several manners. The following paragraphs will show how credibility, auditability and fittingness were assessed (Guba, 1981), and the weaknesses that existed will be examined in the discussion chapter.

Assessing credibility

Credibility can be defined as how vivid and faithful the description of the phenonmenon is (Beck, 1993) to the point where the people who had that experience should be able to recognize it as their own (Guba & Lincoln, 1989).

As the researcher was one of the facilitators of the intervention the participants may not have felt at ease to give negative feedback, or equally, they may have felt obliged to give positive feedback, thereby reducing the credibility of the data (Lincoln & Guba, 1985). In order to reduce this risk, before the beginning of each interview, it was made clear to the participants that honest answers were important, even if this meant giving negative feedback, which would be equally important to enable future improvements to the intervention. Moreover, in spite of the interview schedule, liberty was given to elaborate on subjects the participants wished to approach, in order to allow space for any type of information to emerge. Precautions were taken not to influence the interviewees in any way or to ask leading questions. Furthermore, member-checking to ensure that participants were not trying to please the researcher was performed by having half the interviews carried out by the researcher and another half by an independent counsellor in order to enable a comparison of responses between interviewers. This technique is also known as triangulation between researchers (Glaser & Strauss, 1967; Krefting, 1991; Shenton, 2004). Lincoln & Guba (1985) also suggested that member checks could be performed by sharing the data with the study participants in order to check their accuracy and by the length of time that the investigator is engaged with the participants. The results were not shared with all the participants, but some were present at oral presentations where the results were presented with subsequent positive feedback from them, and the interviews were transcribed verbatim and the transcript rechecked with the original recording. Finally, although interviews were not carried out for more than 30 minutes, the participants and their difficulties and feedback were well known to the researcher, who had spent 18 hours with each paticipant during each intervention and 522 hours in general during the 29 interventions. The credibility of the data could also be verified by comparing quotes from different participants, which showed that in general there was a consensus of opinions and when opinions diverged, credible explanations existed.

Assessing auditability

Auditability, or the ‘audit trail’ (Guba & Lincoln, 1989) is important to enable another researcher to follow the decision trail and make the same enquiry in rhe same setting if required (Beck, 1993).

Details of how the samples were selected, the recruitment process and how the data was collected and analysed was presented in previous sections of the methodology chapter, sections 3.4, 3.5, 3.7 and 3.8. An example of the thematic category structure used for content analysis, an interview transcript and how it was analysed, and the results of the content analysis have been included in appendix 28.

Assessing fittingness

Fittingness or transferability looks at how well the findings have meaning to others in similar situations outside the the study situation (Beck, 1993). Therefore, the participants, the physical environment and context of data collection should be described in order to allow the reader to 'visualise the context from which the theory and its specific categories were developed' (Chiovitti & Piran, 2003). Morse and Singleton (2001), however, argue that it is not the setting or sample that should be transferable, but the theory. Therefore, if the problem exists in a different setting, then the theory should be transferable.

In this study, the site and participants were described in section 3.3 and 3.4. The fittingness could also be obtained by comparing the results with other Portuguese studies, with similar findings (Soares, 2010; Pereira, 2011) and although participants were not evenly distributedin terms of location and profession, efforts were made to have a variety of professional categories and from different health institutions from different parts of the country.

3.9 TIMETABLE OF EACH PART OF THE RESEARCH

Following is a timetable of each phase of the research study and by whom the work was carried out. This research was carried out in the regime of part-time.

What was done	Date	By Whom
Submission of research proposal to the Calouste Gulbenkian Foundation	Jan-05	Carol Gouveia Melo
Signature of Contract with the Calouste Gulbenkian Foundation	24.5.2005	
Letters of invitation to hospitals to participate in study	Jul-05	Carol Gouveia Melo
Survey to health care workers who care for patients with a terminal condition on causes of burnout, causes of professional fulfilment and fears in relation to life and death	Jul-05	Carol Gouveia Melo
Construction of questionnaires	July to September 2005	Carol Gouveia Melo
Pilot test of questionnaires	Oct-05	Carol Gouveia Melo
Group interventions + collection of 1st set of questionnaires	October 2005 to February 2008	Carol Gouveia Melo (module 1) and Helena Aitken (Module 2)
Collection of Control Group	January 2007 to May 2008	Carol Gouveia Melo
Join Kent University for PhD	Aug-07	Dr David Oliver Supervisor
Data processing of part of quantitative data	February to June 2008	Carol Gouveia Melo
Data collection of 2nd set of quantitative questionnaires	February 2006 to September 2008	Carol Gouveia Melo
Interviews	September and October 2008	Carol Gouveia Melo and Claudia Farinha
data processing of quantitative data	January to March 2009	Carol Gouveia Melo
transcript of interviews	March-April 2009	Carol Gouveia Melo
Content analysis of qualitative written answers and interviews	April-May 2009	Carol Gouveia Melo
Presentation of poster at the 11th Congress of the European Association of Palliative Care	May-09	Carol Gouveia Melo, David Oliver
Report to Calouste Gulbenkian Foundation	Jun-09	Carol Gouveia Melo
Oral presentation at the 16th Congress of the European Association for Psychotherapy		Carol Gouveia Melo
Oral presentation at the 5th Portuguese National Congress of Palliative Care		Carol Gouveia Melo
Long term support sessions with written diary * (it was decided later not to include this part in the PhD study)	Jan to October 2010	Carol Gouveia Melo
In meeting November 2010 with Jenny Billings as co-supervisor, it was decided not to include long term support sessions in PhD study	Nov-10	Carol Gouveia Melo, David Oliver and Jenny Billings
Publication of peer reviewed article: "Can emotional support for health care workers to cope with death anxiety reduce burnout and improve patient care?" (Journal of Palliative Care, 24:4 Winter 2011)	Nov-11	Carol Gouveia Melo, David Oliver
Jenny Billings joins officially as co-supervisor	Mar-12	
Publication of peer reviewed article: Gouveia e Melo, C. & Oliver, D., 2012. Assessing burnout in portuguese health care workers who care for the dying:validity and reliability of a burnout scale using exploratory factor analysis. *Psychology, Community & Health,* Volume 1(3), pp. 257-272.	Nov-12	Carol Gouveia Melo, David Oliver
Write up thesis	Jan 2011 to July 2013	Carol Gouveia Melo

TABLE 10 - TIMETABLE OF THE EXECUTION OF EACH PHASE OF THE RESEARCH STUDY

As can be seen in the above table, every part of the research was carried out by myself, with the exception of the 2nd module of the intervention and half of the interviews. Half the interviews were carried out by an independent therapist due to the the need of triangulation (Glaser & Strauss, 1967; Krefting, 1991; Shenton, 2004), as discussed in section 3.7 on assessment procedures and data collection. The course was also given by the author of the research and Helen Aitken, because she was the author of the course.

3.10 ETHICAL ISSUES

In Portugal, ethical consent is always required for any research involving the patients, and only sometimes required for research involving the hospital personnel. In this research project, ethical consent from the hospital administration was only required for the control group (appendix 16), who filled in the questionnaires but did not take part in the the intervention. For the experimental group, the clinical director of the unit was contacted by mail with a letter of invitation, explaining the research (appendix 17). The directors who were interested, agreed to propose the intervention to the HCWs of the unit, and their participation in the intervention was voluntary. As most of the costs of the intervention were covered by the Calouste Gulbenkian Foundation, it was possible to offer the course to the team members interested for a minmal fee of €60 instead of €300. This represented an incentive for those who were interested in participating, but as participants were not being paid to participate, it was not considered a bias to the sample. It could be argued however, that as participants had to pay to participate, it could have excluded those who were financially impoverished, thereby affecting their free and informed consent (Shields & Pearn, 2007) and consequently introducing a middle income bias. This could have been the case of the nursing aides, whose income was lower than that of nurses.However, as shown in the results section, this did not seem to be the case, as the ratio of nursing aides/nurses was representative of hospital staff. Ethical consent was also received from the Research and Ethics Committee of the Kent Institute for Health and Medical Sciences / Centre for Professional Practice at the University of Kent but due to many changes in the departments and changes in personnel the form and letters could be located. However the Centre has confirmed that the necessary permission was given, as confirmed by Committee members who were present and are still active in the Centre (appendix 29). Acceptance to participate in the intervention and return the questionnaires was taken as a form of consent. However, an information sheet with full details of the study, data protection and anonimity was provided to participants of both the intervention and control group (appendix. 3 and 5).

Permission for carrying out the interviews was carried out by contacting the head nurse of each department by phone, explaining the purpose and procedure of the interviews and explaining that participation was voluntary. Anonymity of the transcripts was ensured. The head nurse was given a list of all participants and informed each one verbally and gathered a list of participants willing to participate. A date and time was set. Upon arrival at the institution, the interviews were carried out one at a time, in a room with privacy. The purpose of the interview was explained again and the participants were reminded that their participation was entirely voluntary, anonymous and they were free to leave at any time. Permission was requested to tape the conversation and participants were informed that the recording could be stopped at their request.

Confidentiality of data was assured by the use of an identification number only – and the names and list of the numbers was kept securely by the researcher. Participants were not required to put their name on the questionnaire unless they wished to be identified by the researcher in order to obtain the results of their questionnaire. The questionnaires were handed directly from the participant to the researcher or were left in a sealed envelope for her to pick up. The quantitative data from the questionnaires were inserted into SPSS and the qualitative data was transcribed and processed by NVivo and the data was kept in the personal computer of the researcher with a secure password. The original questionnaires were filled securely.

To ensure the well-being of the participants, space was given by the facilitators, at the beginning and end of each day of the intervention and the facilitators' telephone numbers and e-mails were provided to each participant. Individual time was also given to participants whenever needed. The same precautions were taken with the interviews. After the interview, participants were asked how they felt and time was given for the participant to talk freely. This was done as a form of debriefing.

3.11 CONCLUSION

In conclusion, this study was performed using a mixed methods approach using a quasi-experimental design. The independent variable was an intervention designed to reduce death anxiety and burnout, and to increase the quality of the helping relationship between HCWs and patients/families and HCWs' personal well-being at an existential level. Two experimental groups were used, with HCWs working in and out of palliative care. The aim was to obtain at least 60 participants in each experimental group and an equivalent amount for the control group. Only the group working with patients with a terminal condition out of palliative care units had a control group. Three questionnaires were used to assess their levels of burnout, quality of helping relationship and personal well-being. These contained questions on a Likert scale for quantitative analysis and open-ended questions for qualitative analysis. Interviews were also performed for qualitative analysis. The questionnaires were submitted to validation and reliability tests. Statistical qualitative analyses were performed using SPSS and NVivo.

The following chapter will show the results of the sample recruitment, the validation of the questionnaires and the statistical and qualitative analyses of the collected data.

4. QUANTITATIVE RESULTS

CHAPTER OUTLINE

The first section of this chapter begins with the participants for the quantitative part of the research and describes the two experimental groups and the control group.

The second section contains the quantitative results. Baseline studies were performed using t-tests to ensure that the experimental and control groups were comparable. This was followed by overall results regarding the general effect of the intervention. Having established the positive effect of the intervention, more specific analyses were performed, namely a comparison of results between different areas (PCUs and other units, age, profession), the effect on burnout and death anxiety and finally the relationships that exist between burnout, death anxiety, personal well-being and the HCWs' perception of quality of their helping relationship skills.

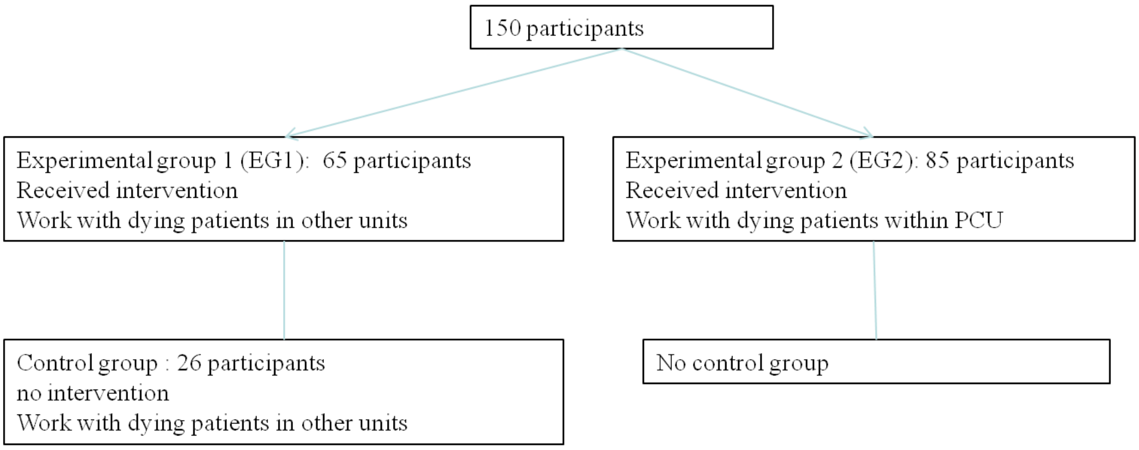
4.1 PARTICIPANTS

Of the HCWs approached during the period of recruitment, 208 health care workers wished to participate in the intervention group and were allocated to a 6 days (36 hours) group therapy/training with a minimum of 6 and a maximum of 10 participants per group. The course was given to 29 groups with an average of 7 participants each.

Of these participants, 150 participants completed both pre and post-intervention questionnaires and 94 answered the qualitative questions. Their ages ranged from 21 to 67 but 33% were between 23 and 27 years old. There were 87 nurses (58 per cent), 30 nursing aides (20 per cent), 12 psychologists (8 per cent), 8 doctors (5 per cent), and 13 HCWs of other professions (9 per cent) (social workers, physiotherapists, chaplains, nutritionists, and occupational therapists). This sample of nurses and nursing aides mirrored the wider hospital personnel breakdown, as there was approximately 1 nursing aide for every 3 nurses. In all, 134 (89 per cent) were female and 16 (11 per cent) were male. A total of 85 (57 per cent) worked in palliative care units, and 65 (43 per cent) worked with patients with a terminal condition but not in a palliative care unit. 87 (58%) had a university degree, 28 (18,7%) had a post-graduate and the others were undergraduates; due to the higher number of nurses, nursing aides and females in each unit that received the training, it was not possible to control for order effects: nurses, nursing aides and females account for the larger part of the population (>75%). It took three months to collect all the post-training questionnaires.

Of the HCWs approached for the control group, 99 participants filled in the first questionnaires, but 27 questionnaires were excluded for various reasons. Some had participated in the course elsewhere, others failed to fill in all the questionnaires and others contained too many missing data. Of the remaining 72, 26 returned the second questionnaire which was distributed to them after an interval of 4 months. These ranged in age from 22 to 54. They worked with oncology patients, but not in a palliative care unit. Of these, 23 (88 per cent) were nurses and 4 (12 per cent) were nursing aides. Of the 150 participants in the experimental groups, only 65 of them— those caring for patients with a terminal condition but not in a palliative care unit (EG1) — were comparable to the control group.

Following are figures and tables with information of the sample:



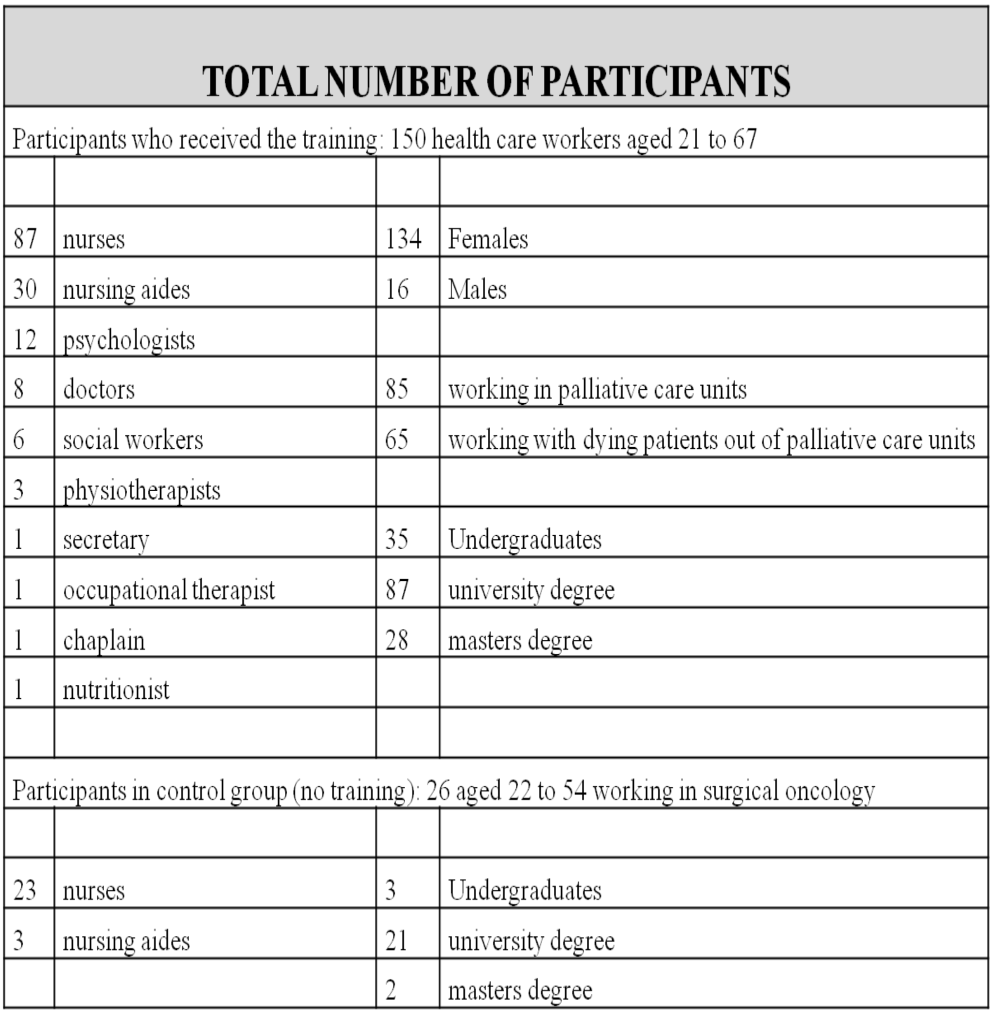
EG1: HCWs working with patients with a terminal condition in other units

EG2: HCWs working with patients with a terminal condition within PCUs

PCUs: Palliative care units

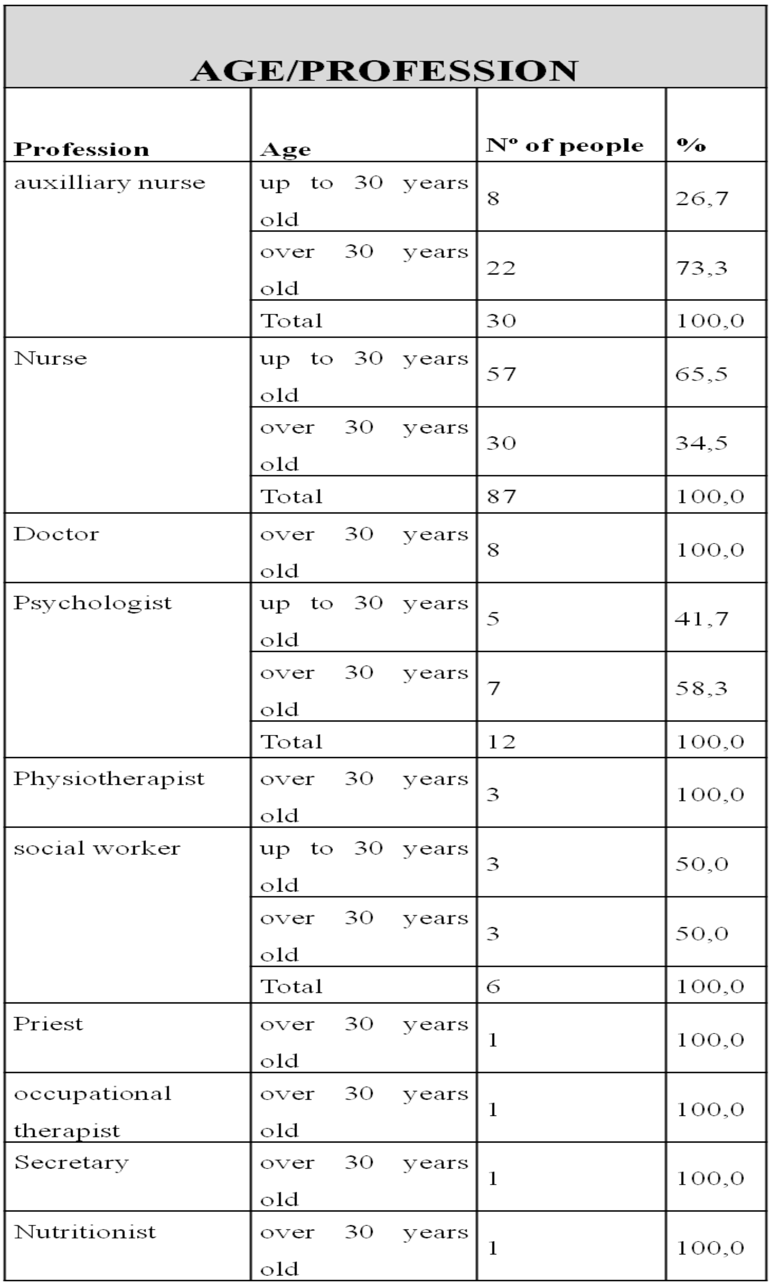
NB: of the 72 participants who participated in the baseline studies for the control group, 26 answered the second questionnaire 4 months later, thus the discrepancy.

FIGURE 11 - FINAL NUMBER OF PARTICIPANTS



TOTAL NUMBER OF PARTICIPANTS			
Participants who received the training: 150 health care workers aged 21 to 67			
87	nurses	134	Females
30	nursing aides	16	Males
12	psychologists		
8	doctors	85	working in palliative care units
6	social workers	65	working with dying patients out of palliative care units
3	physiotherapists		
1	secretary	35	Undergraduates
1	occupational therapist	87	university degree
1	chaplain	28	masters degree
1	nutritionist		
Participants in control group (no training): 26 aged 22 to 54 working in surgical oncology			
23	nurses	3	Undergraduates
3	nursing aides	21	university degree
		2	masters degree

TABLE 11 - PARTICIPANTS - NUMBER



AGE/PROFESSION			
Profession	**Age**	**Nº of people**	**%**
auxilliary nurse	up to 30 years old	8	26,7
	over 30 years old	22	73,3
	Total	30	100,0
Nurse	up to 30 years old	57	65,5
	over 30 years old	30	34,5
	Total	87	100,0
Doctor	over 30 years old	8	100,0
Psychologist	up to 30 years old	5	41,7
	over 30 years old	7	58,3
	Total	12	100,0
Physiotherapist	over 30 years old	3	100,0
social worker	up to 30 years old	3	50,0
	over 30 years old	3	50,0
	Total	6	100,0
Priest	over 30 years old	1	100,0
occupational therapist	over 30 years old	1	100,0
Secretary	over 30 years old	1	100,0
Nutritionist	over 30 years old	1	100,0

TABLE 12 - PARTICIPANTS - PROFESSION/AGE OF INTERVENTION GROUP

4.2 QUANTITATIVE RESULTS

4.2.1 COMPARISON OF CONTROL AND INTERVENTION GROUPS AT BASELINE

Baseline studies mentioned in the methodology were performed by comparing the results of the 72 participants of the control group, who filled in the first set of questionnaires, and the results of the first set of questionnaires of the 65 participants from the EG1. The means of the first set of questionnaires of the 72 participants of the control group and the 65 participants of the experimental group were compared using independent samples T-Test. Results showed no significant differences between the scores with the exception of “Fear of dependence, physical degradation and loss of control”, where participants from the control group scored significantly higher than the experimental group. These results show that the control group is comparable to the experimental group, with the exception of the above mentioned dimension, where caution is required when interpreting the results:

Name of Questionnaire	Factors derived from factor analysis using PCA	T1 CG n=72	SD	T1EG1 n= 65	SD	Sig. (2-tailed)
B.L. Relationship Inventory	Empathy and Congruence	4.23	0.69749	4.37	0.6958	Ns
	Unconditional Acceptance	4.93	0.62135	4.98	0.58744	Ns
	Avoidance mechanisms	2.94	0.67239	2.97	0.72523	Ns
	Distance and impatience towards patient	1.85	0.53064	1.96	0.53007	Ns
Personal Wellbeing	Self-Confidence, dignity and meaning in spite of adversity and illness	4.35	0.58528	4.37	0.70263	Ns
	Close relationships and personal well-being	4.7	0.68125	4.69	0.6818	Ns
	Fear of dependence, physical degradation and loss of control	4.25	87095	3.78	0.87774	p < .002
	Self criticism regarding time for family, friends and meaningful activities	3.21	0.7753	3.29	0.70326	Ns
Burnout	Emotional exhaustion	3.47	0.77699	3.31	0.83132	Ns
	Professional fulfilment	4.21	0.61306	4.4	0.64487	Ns
	Depersonalization	2.13	0.3383	1.99	0.65946	Ns

TABLE 13 - BASELINE COMPARISON OF CONTROL AND EXPERIMENTAL GROUP

4.2.2 THE EFFECT OF THE INTERVENTION

150 participants completed the questionnaires at the beginning (T1) and at four months (T2) and gave their assessment in retrospect, of their perception of scores at T1 (T1p):

- T1 = before intervention
- T2 = at least 4 months and up to 7 months after the intervention
- T1p = assessment in retrospect of their perception of scores at T1

The results are shown in table 19. Questions answered were on a Likert scale from 1 to 6 where 1 = disagree completely and 6 = agree completely:

Name of Questionnaire	Factors derived from factor analysis using PCA	T1p	SD	T1	SD	T2	SD	T1 and T2			T1p and T1		
								t (149)	p < (2-tailed)	η2	t (149)	p < (2-tailed)	η2
B.L. Relationship Inventory	Empathy and Congruence	4.02	0.7087	4.27	0.68308	4.48	0.66514	-4.4	0.001	0.11	4.39	0.001	0.11
	Unconditional Acceptance	4.91	0.545	5	0.56051	5.14	0.5295	-3	0.003	0.06		ns	
	Avoidance mechanisms	2.87	0.6478	2.93	0.67678	2.69	0.6901	4.68	0.001	0.06		ns	
	Distance and impatience towards patient	1.83	0.5544	1.87	0.53892	1.72	0.5616	3.2	0.002	0.06		ns	
Personal Wellbeing	Self-Confidence, dignity and meaning in spite of adversity and illness	4.33	0.6245	4.46	0.64593	4.73	0.57904	-5.9	0.001	0.19	2.62	0.01	0.04
	Close relationships and personal well-being	4.54	0.6775	4.74	0.6634	4.86	0.61892	-2.3	0.022	0.03	3.7	0.001	0.08
	Fear of dependence, physical degradation and loss of control	3.86	0.8021	3.8	0.88017	3.49	0.88384	5.58	0.001	0.17		ns	
	Self criticism regarding no time for family, friends and meaningful activities	3.32	0.6879	3.21	0.72773	3.16	0.6753		ns		-2.07	0.04	0.03
Burnout	Emotional exhaustion	3.1	0.793	3.1	0.80445	2.89	0.81097	3.5	0.001	0.07		ns	
	Professional fulfilment	4.33	0.5929	4.44	0.60115	4.62	0.58555	-4	0.001	0.09	2.16	0.033	0.03
	Depersonalization	1.74	0.5914	1.81	0.61849	1.63	0.60005	4.03	0.001	0.1		ns	

T1p: “my perception today (4 months after training) of how I was before training”); T1: “How I feel today” (immediately before training); T2: “How I feel today” (4 months or more after training); SD: standard deviation; η2: eta square

TABLE 14 - MEAN SCORES AND STANDARD DEVIATION - GROUP WITH TRAINING

These results can also be shown graphically in Figure 13:

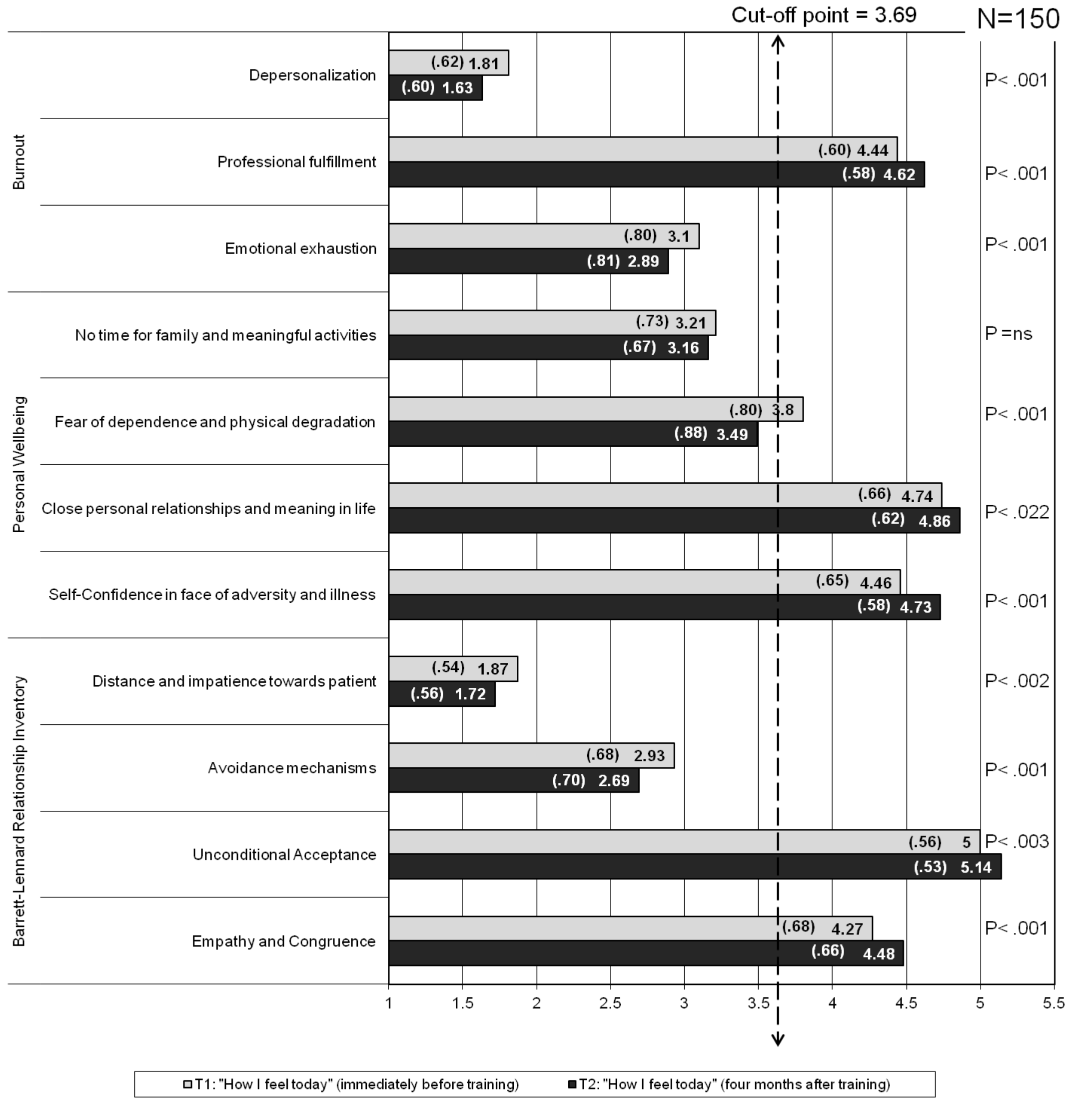


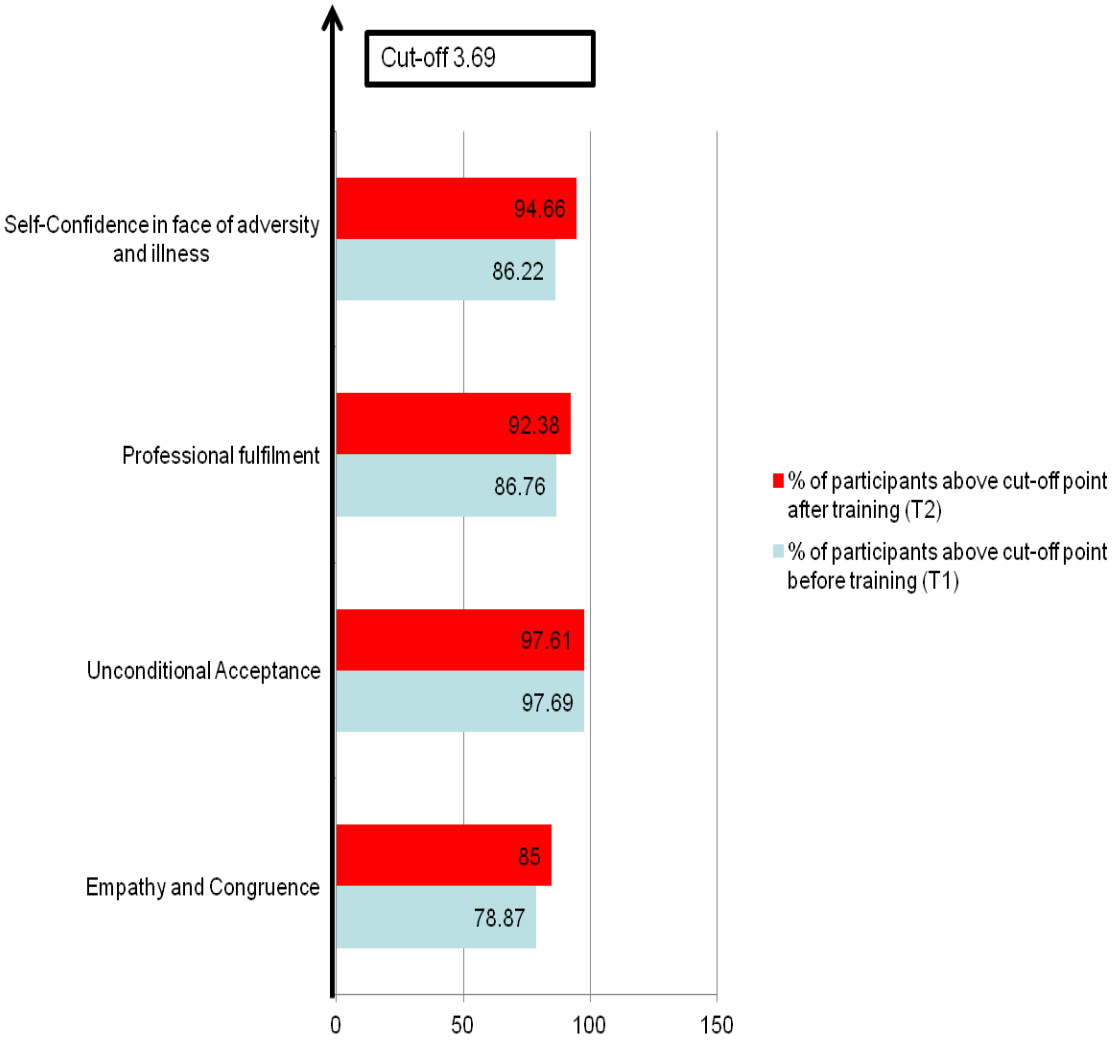
FIGURE 12 - COMPARISON OF MEAN SCORES (AND STANDARD DEVIATION) BEFORE TRAINING AND FOUR MONTHS AFTER (N= 150)

This comparison uses a cut-off point of 3.69. As explained in the methods section the cut-off point for these three questionnaires was calculated as the mean of the 11 factors of the 3 questionnaires, separating positive and negative factors, i.e. the mean of the negative factors and the mean of the positive factors were calculated and then these two figures were summed up and divided by two.

These results show a significant improvement in all factors assessed, with the exception of “no time for family and meaningful activities”. This figure also shows that most negative factors were below the cut-off point, especially depersonalization and distance and impatience towards patients, and all the positive factors were above the cut-off point, especially “unconditional acceptance”. Fear of dependence and physical degradation was the only negative factor that was above the cut-off point before the intervention and after the intervention this was reduced to just below the cut-off point.

Cumulative Frequencies of Intervention Group (T1/T2)

The following results take into consideration the cut-off point of 3.69 again and look at the percentage of participants above the cut-off point before and after the training: (fig 3):



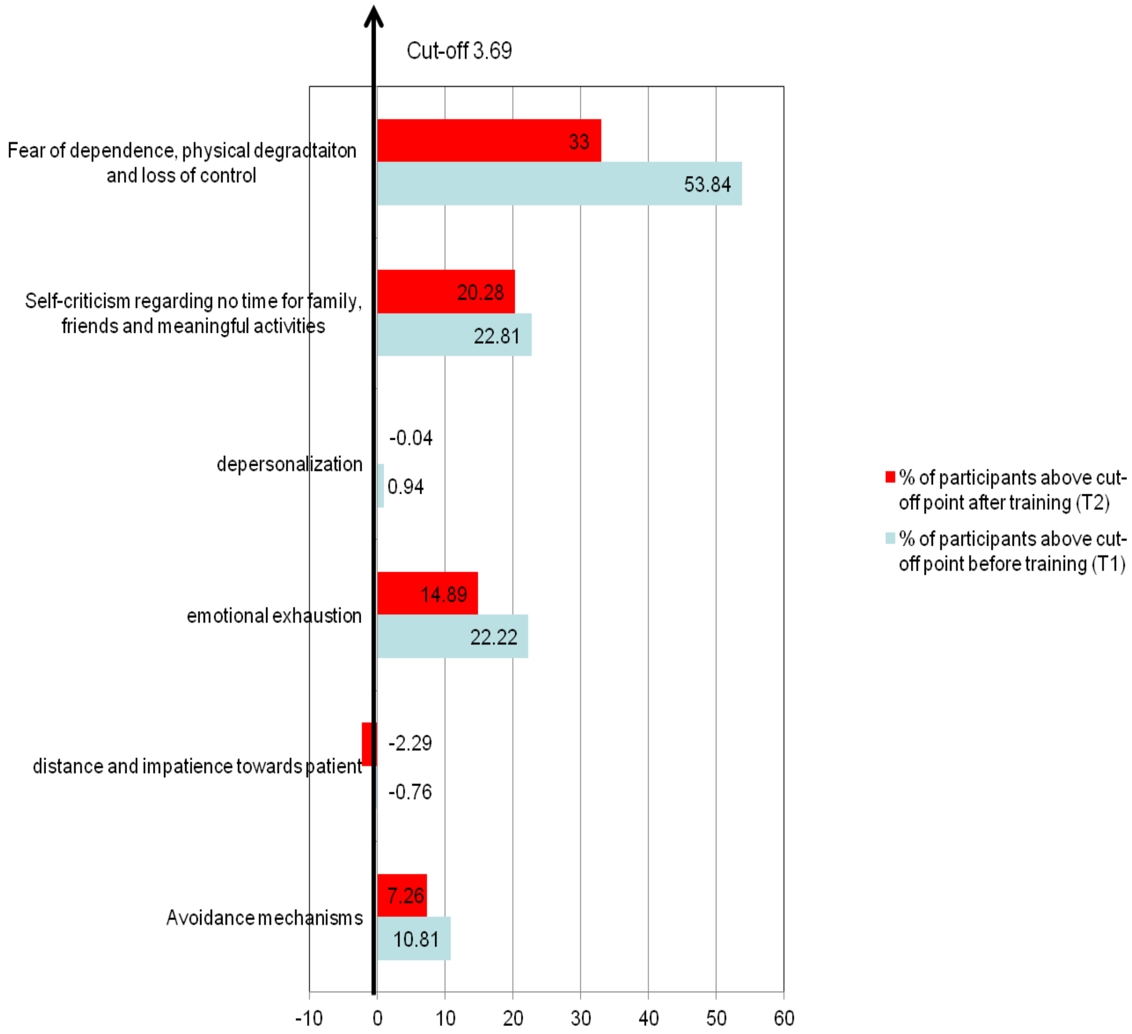


FIGURE 13 - GRAPHIC VISUALIZATIONS OF IMPROVEMENT IN % OF POPULATION IN RELATION TO CUT-OFF POINT

Consideration of this cut-off point shows that participants were found to have changed in several aspects: the greatest reduction was seen in fear of dependence and physical degradation which decreased 20.84%, followed by self-confidence in face of adversity and illness, which increased 8.44%, emotional exhaustion which decreased 7.33%, empathy and congruence which increased 6.13% and professional fulfilment which increased 5.62%. Thus the course seems to have helped the participants particularly in these aspects. For the other areas, there were relatively small changes, although as seen in fig 13, the only non-significant result was in relation to self-criticism regarding no time for family, friends and meaningful activities.

It is clear to see from these diagrams how the positive factors increased from T1 to T2 and the negative factors decreased. Although there was a statistical difference in depersonalization, the scores were so low in the first place, that the difference is not noticeable in the graphs of fig 14. Unconditional acceptance also shows no change in this graph. However, if we analyse the data in a different way, taking into consideration the standard deviation, it is possible to see all factors, including unconditional acceptance and depersonalization shift into the direction of improvement:

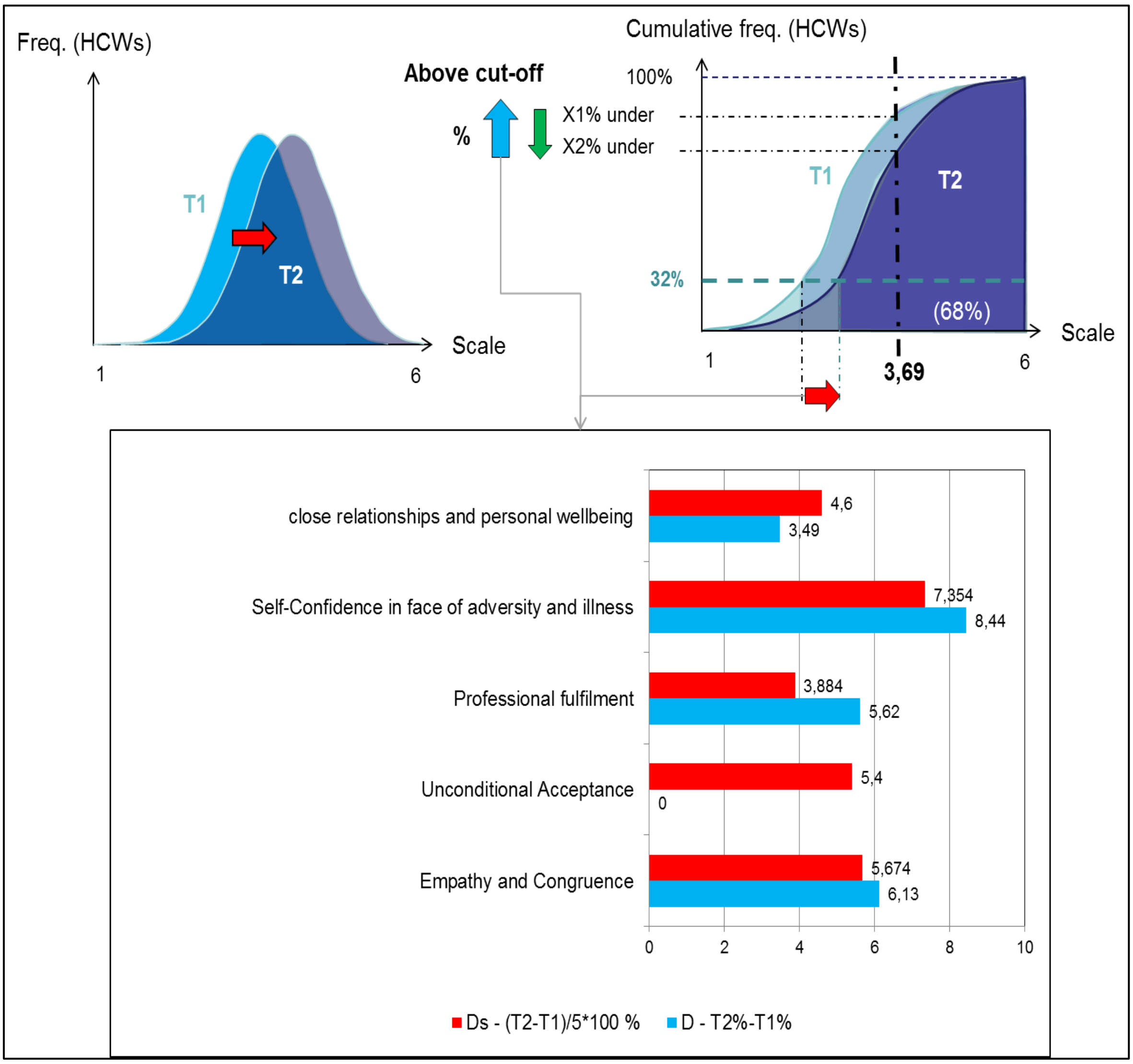


FIGURE 14 - SHIFT OF % ABOVE CUT-OFF AND SCALE SHIFT AT POINT 68% OF THE SAMPLE (POSITIVE FACTORS)

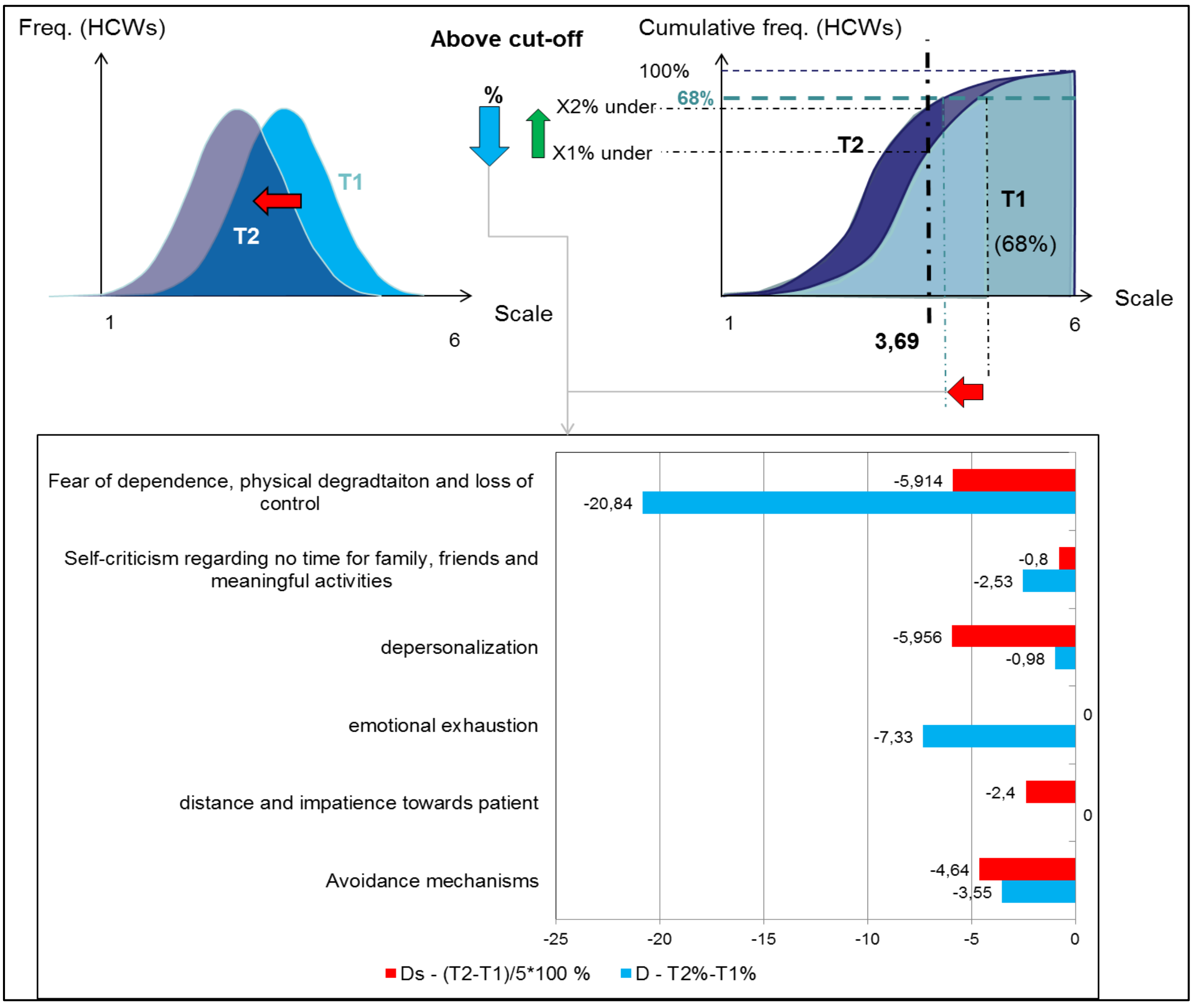


FIGURE 15 - SHIFT OF % BELOW CUT-OFF AND SCALE SHIFT AT POINT 68% OF THE SAMPLE (NEGATIVE FACTORS)

These results show that there was a significant improvement from T1 to T2 in all areas, except for self-criticism regarding no time for family, friends and meaningful activities. There was however, a significant difference in this factor between T1 and T1p, as shown in the following section.

Changes in Perception with the Training

The participants assessed, in retrospect, their previous scores – T1p. This was performed to understand if the intervention also changed their criteria of self evaluation. Comparison of these scores showed a significant change in several areas.

In relation to the 3 factors of burnout a significant change occurred only in relation to professional fulfilment. After the intervention, HCWs gained a different notion of professional fulfilment and realized that before, they were not as happy at work as they thought they were.

In relation to Personal Well-being, they became more aware of the meaning of close personal relationships and giving time to family, friends and meaningful activities and realized they were worse than they had originally thought.

In relation to their perception of Helping Relationship skills, the only significant change was in empathy and congruence. The intervention allowed them to have a deeper understanding of the patient with a terminal condition and they also became more aware of how certain issues or conversations made them feel uncomfortable.

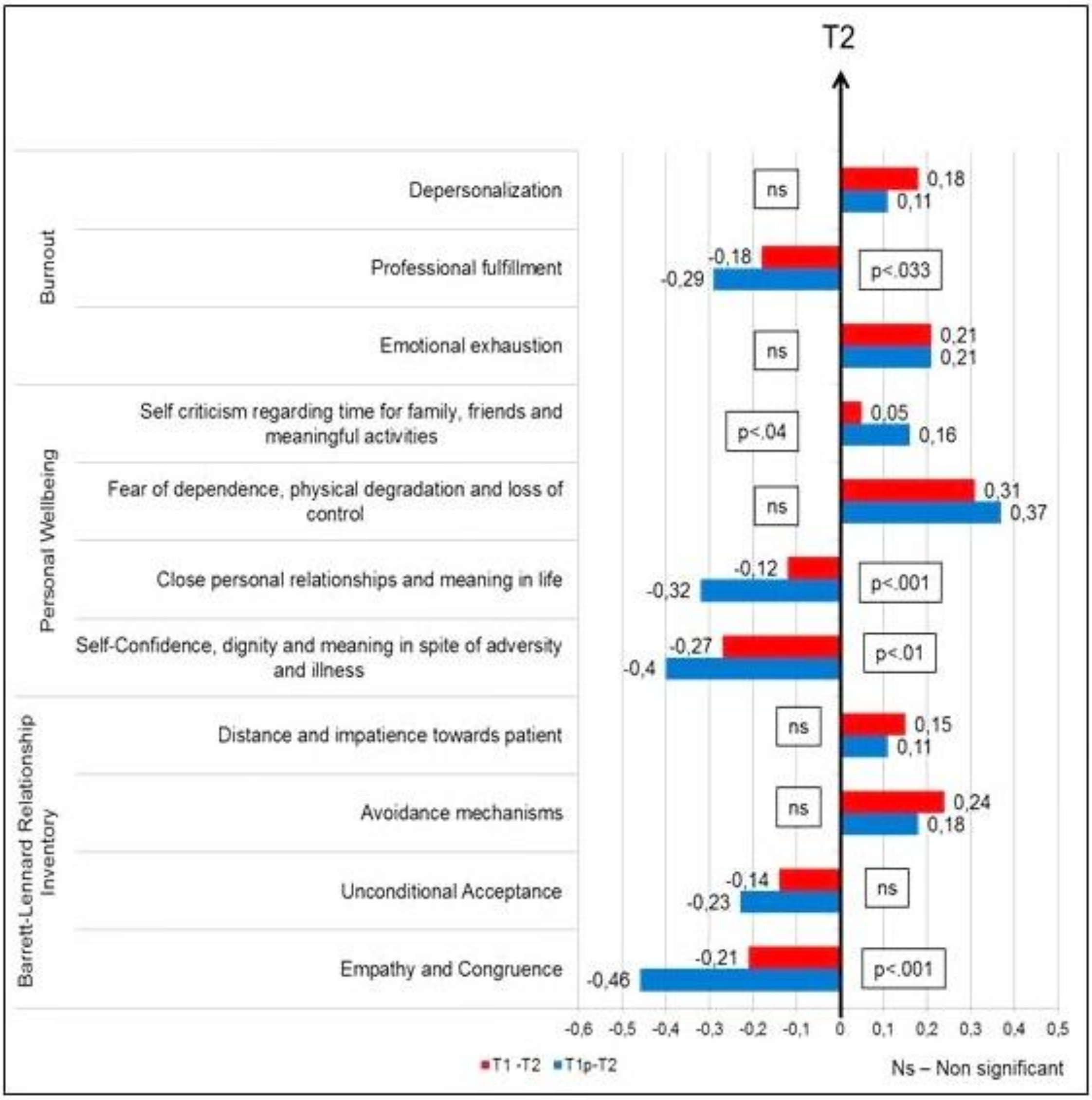


FIGURE 16 - GENERAL COMPARISONS OF MEANS – DIFFERENCES IN PERCEPTION (T1/T1P)

The results show that there were significant changes with regard to most of the positive factors, except for "unconditional acceptance" where HCWs scored very high in this area on both occasions. The results for the negative items only showed significant change for the area of "self criticism regarding time for family, friends and meaningful activities". Although comparison of the general population showed that the training had no significant effect on actual changes in this area (see fig. 13), it seems that HCWs did become aware of the importance of this factor for their general well-being, and realised that they were perhaps not doing as well as they had originally thought.

Control Group (N = 26)

Following are the mean scores of the 26 participants (control group who completed both questionnaires with an interval of 4 months) who did not do the training (Likert scale from 1 to 6 where 1 = disagree completely and 6 = agree completely). T-tests for all factors of the control group were non-significant.

Name of Questionnaire	Factors derived from factor analysis using PCA	T1	SD	T2	SD	T-Test
B.L.Relationship Inventory	Empathy and congruence	4.15	.61919	4.25	.59547	Ns
	Unconditional acceptance	4.83	.61670	5.04	.44098	Ns
	Avoidance mechanisms	2.98	.71141	2.78	.66911	Ns
	Distance and impatience towards patient	1.93	.57326	1.72	.49414	Ns
Personal Wellbeing	Self-confidence, dignity and meaning in spite of adversity and illness	4.36	.70141	4.36	.56786	Ns
	Close relationships and personal well-being	4.66	.65061	4.83	.62893	Ns
	Fear of dependence, physical degradation and loss of control	4.17	.77279	4.14	.81635	Ns
	Self criticism regarding time for family, friends and meaningful activities	3.24	.68908	3.19	.70158	Ns
Burnout	Emotional exhaustion	3.21	.57409	3.18	.74442	Ns
	Professional fulfilment	4.35	.59441	4.50	.50849	Ns
	Depersonalization	1.98	.63853	1.85	.53681	Ns

TABLE 15 - MEAN SCORE AND STANDARD DEVIATION OF CONTROL GROUP

The control group (HCWs working in other units) can be compared to a similar group who did receive the training - EG1 (also HCWs working in other units). As discussed in the methodology, there was no control group for EG2 (HCWs working within a PCU). These results are shown in figure 18 and 19.

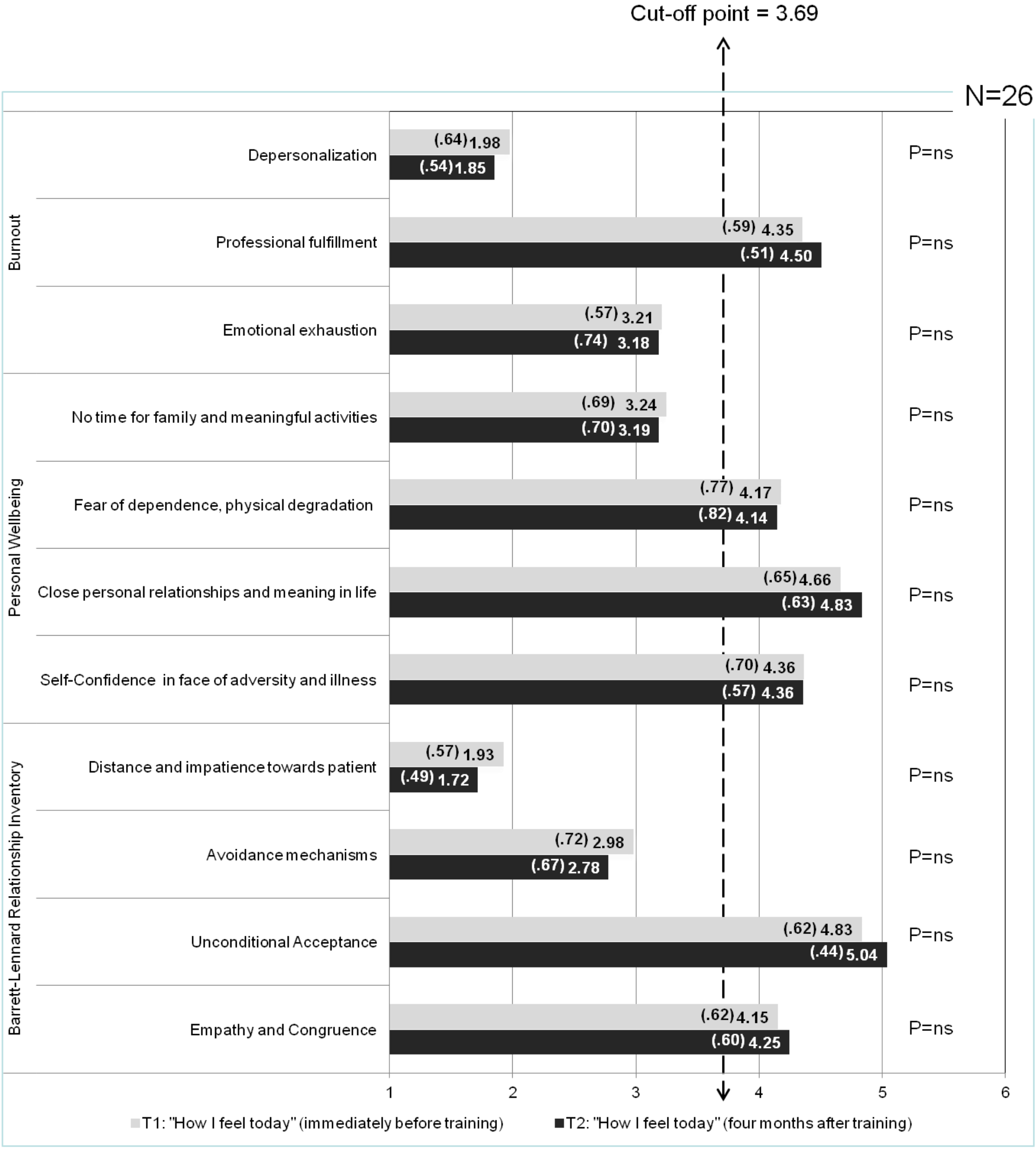


FIGURE 17 - HCWS CARING FOR PATIENTS WITH A TERMINAL CONDITION IN OTHER UNITS, CONTROL GROUP MEAN SCORES AND SD (N=26)

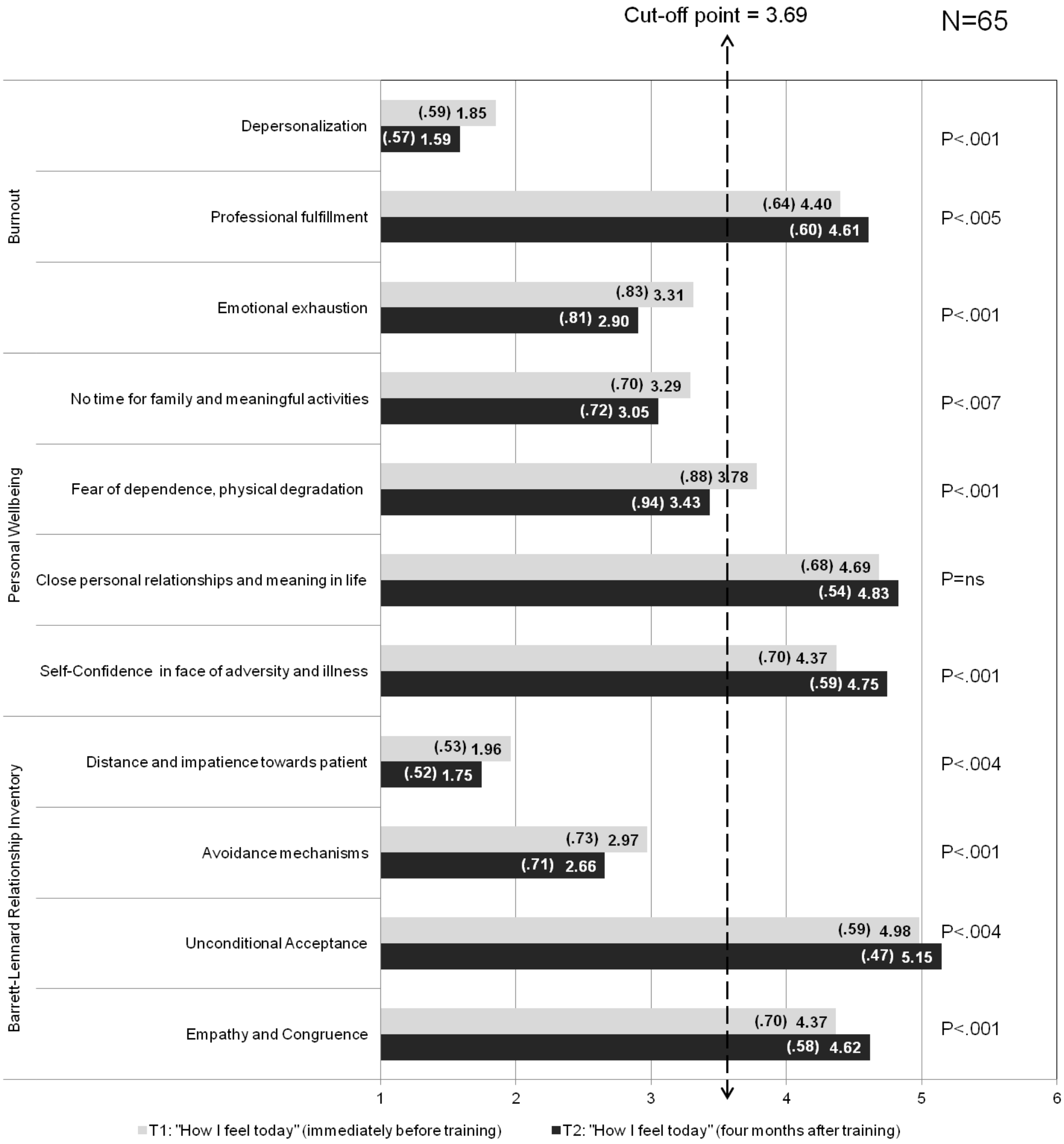


FIGURE 18 - HCWS CARING FOR PATIENTS WITH A TERMINAL CONDITION IN OTHER UNITS, EXPERIMENTAL GROUP 1 MEAN SCORES AND SD (N=65)

These results show that the Control Group, who did not receive any training, did not show any changes in the scores over the 4 month period. This shows that the changes found in the Intervention Group would seem to be due to the training they had received and was not merely due to changes over time.

Section Summary

In conclusion, there is evidence that the training did alter the scores of the participants who received training and these changes were not seen in the Control Group who had received no training. It would seem therefore, that the intervention had an effect on the participants with improved scores. Moreover, there is evidence that the training did increase awareness of the issues involved, as their perception of their knowledge and skills before the training was affected by the training itself.

4.2.3 RESULTS FROM DIFFERENT AREAS OF CARE

Working Within PCUs (Eg1) and in Other Units (Eg2)

As 56.66% of the participants were working within a Palliative Care Unit (PCU) and 43.34% were in other units, it is possible to consider if there were differences in the impact of training depending on their place of work.

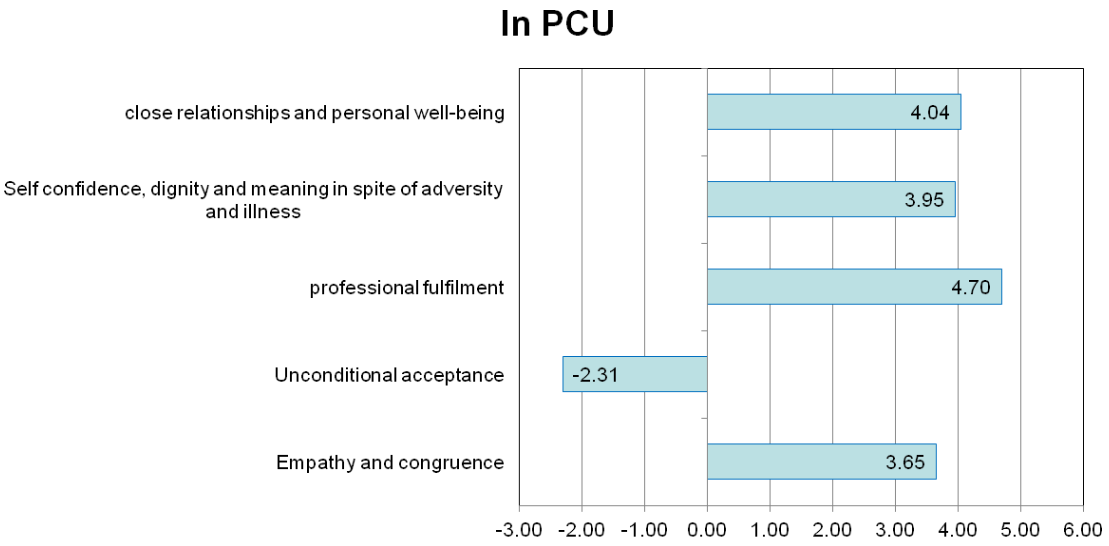
Participants Working Within a PCU

The following table shows the improvement in percentage of HCWs above cut-off point working within a PCU:

HCWs Within PCUs	Cut-off (3,69)			68% of sample above x score			
Positive Dimensions	T1 %	T2 %	Delta (T2-T1)	T1 score	T2 score	Delta (T2-T1)	D(%)
Empathy and congruence	74.47	78.12	3.647	3.765	4.102	0.337	6.74
Unconditional acceptance	98.08	95.77	-2.314	4.69	4.964	0.2739	5.479
professional fulfilment	88.91	93.61	4.7	4.196	4.372	0.1762	3.524
Self confidence, dignity and meaning in spite of adversity and illness	89.81	93.76	3.95	4.207	4.451	0.2442	4.885
close personal relationships and well-being	92.76	96.8	4.041	4.392	4.673	0.2809	5.618
	Cut-off (3,69)			68% of sample under x score			
Negative Dimensions	T1 %	T2 %	Delta (T2-T1)	T1 score	T2 score	Delta (T2-T1)	D(%)
avoidance mechanisms	8.629	4.054	-4.574	3.176	3.122	-0.054	-1.078
distance and impatience towards patient	0	0	0	1.99	1.78	-0.21	-4.195
fear of dependence, physical degradation and loss of control	53.82	31.47	-22.35	4.234	3.665	-0.568	-11.37
self-criticism regarding no time for family , friends and meaningful activities	18.17	20.39	2.219	3.342	3.403	0.0607	1.215
emotional exhaustion	16.86	15.69	-1.177	3.265	3.195	-0.07	-1.4
depersonalization	0	0	0	1.94	1.761	-0.178	-3.567

TABLE 16 - PERCENTAGE OF PARTICIPANTS WITHIN PCUS ABOVE THE CUT-OFF POINT BEFORE AND AFTER INTERVENTION

The following figures show this information in graph format:



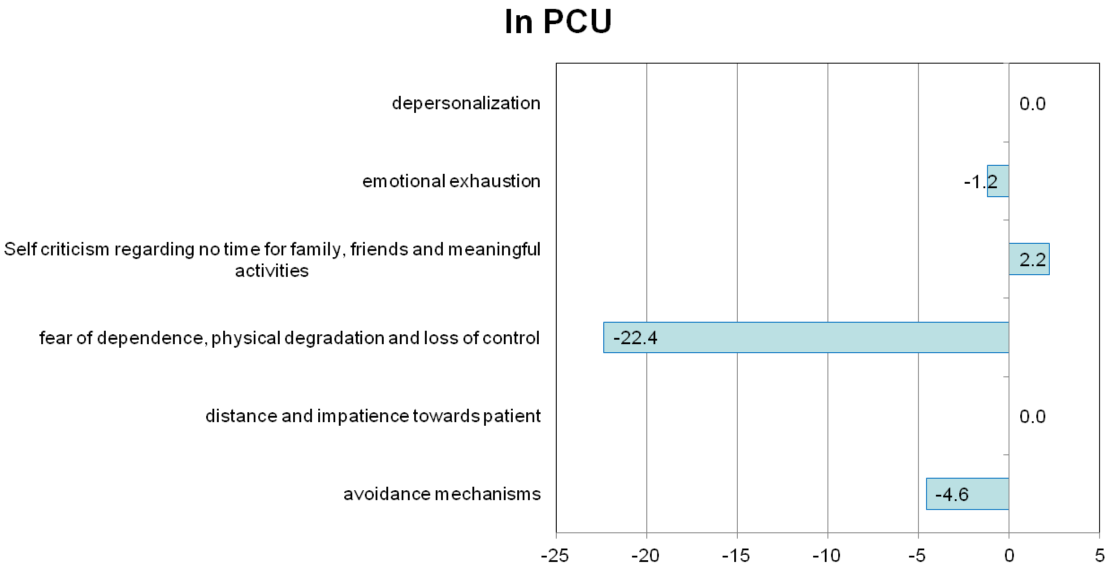


FIGURE 19 - GRAPHIC VISUALIZATION OF DIFFERENCE IN IMPROVEMENT OF HCWS WITHIN PCUS IN RELATION TO % OF POPULATION ABOVE CUT-OFF POINT

These results showed that in the positive factors, HCWs within PCUs improved in all areas, except for unconditional acceptance, although there was an improvement in the means (T1=5.01, SD .54227 and T2= 5.14, SD .57484). In the negative factors, small or no changes occurred, except for fear of dependence, physical degradation and loss of control, where very significant changes occurred: 53.82 of HCWs in PC units were above the cut-off point, and at T2, only 31.47% were. Therefore there was a decrease in 22.35%. In relation to self criticism regarding no time for family, friends and meaningful activities, the scores worsened. HCWs in PCUs were already making efforts to spend more time with family, and these results show that they were not able to make more time, and therefore their self criticism increased. These results will be further discussed in the qualitative results.

The explanation for the negative results in unconditional acceptance when considering the cut-off point and positive results when considering the mean can be understood in the following graphs:

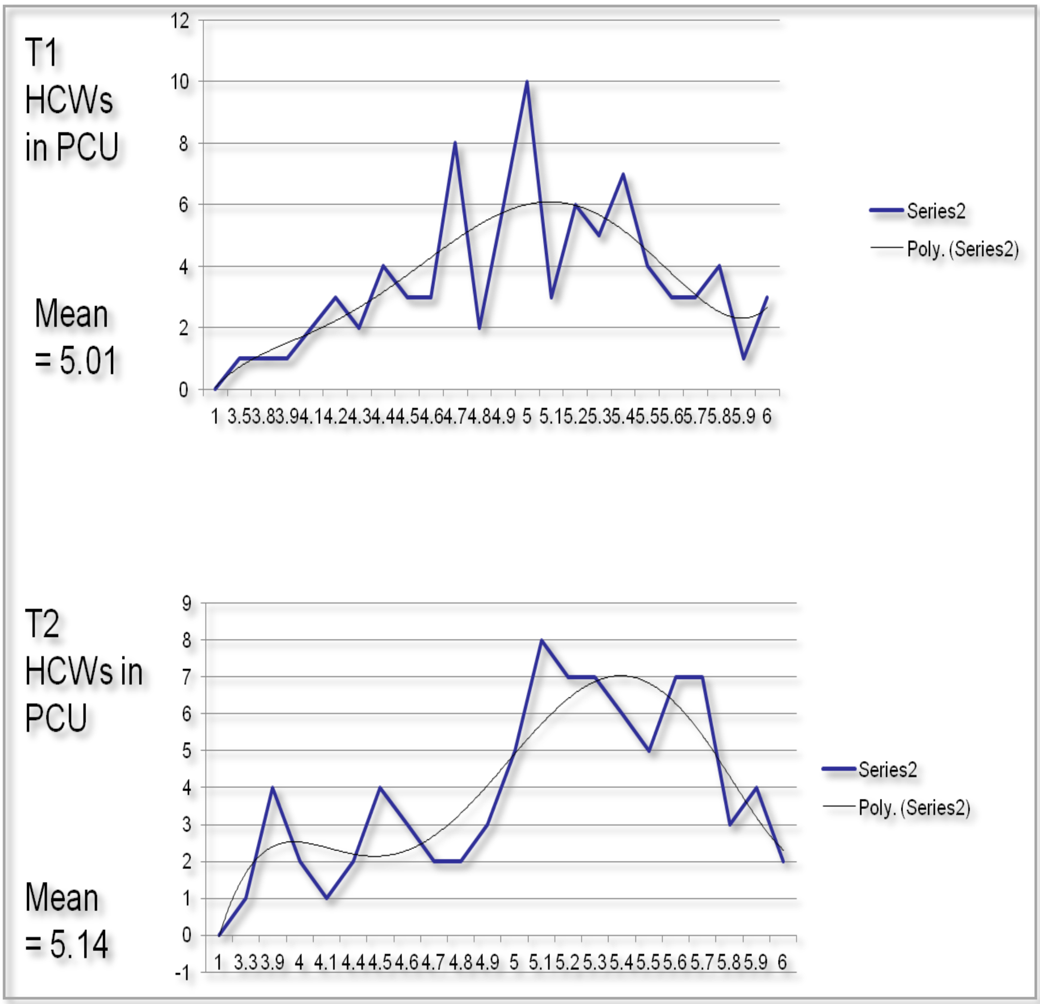
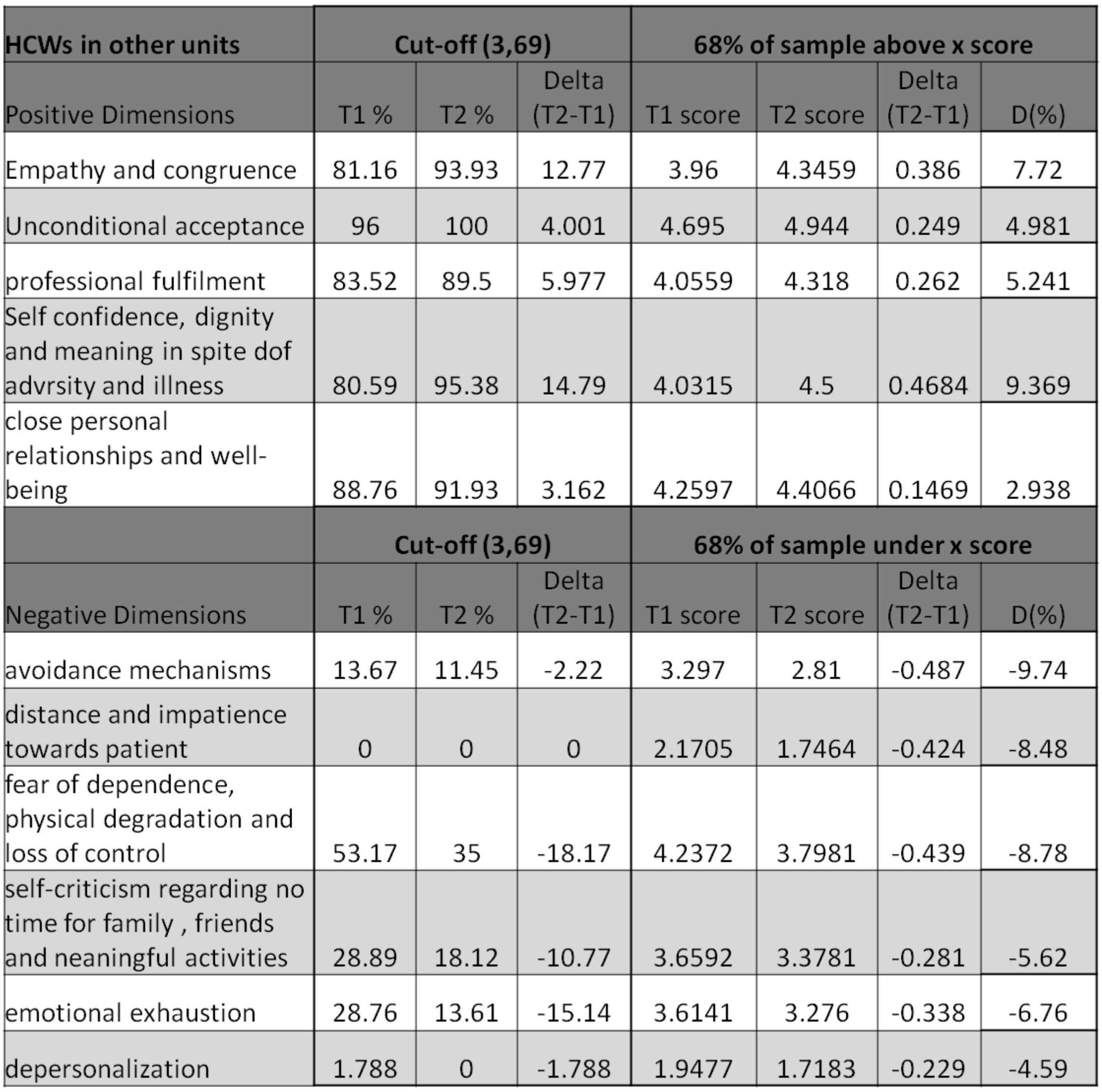


FIGURE 20 - Nº OF PARTICIPANTS PER SCORE – UNCONDITIONAL ACCEPTANCE

These graphs show that before the training, the distribution of scores was a normal bell shape, with few participants below the cut-off point. After the training, the scores polarized, with more scoring below the cut-off point than before, but those scoring above improved significantly in relation to before the training, thereby influencing positively the mean result.

Participants Working in Other Units

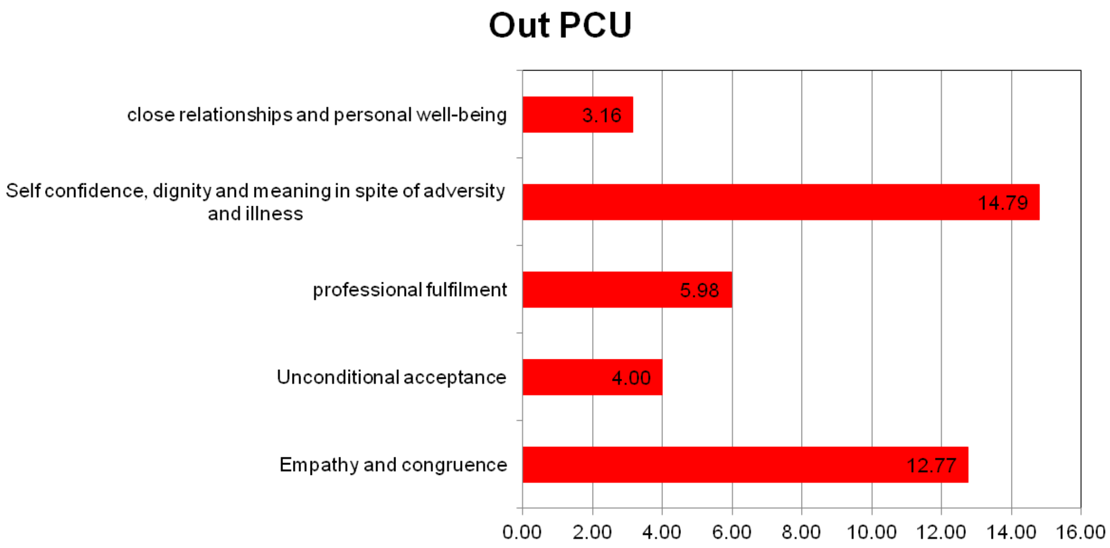
Sixty five participants were working in other areas of work, including haemato-oncology, patients with a terminal condition in a retirement home, a community care team and HCWs caring for patients with a terminal condition from different hospitals in the Alentejo, a large mostly rural area between Lisbon and the Algarve, who were intending to form a palliative care community team. The results are shown in table 17 and fig 22.



HCWs in other units	**Cut-off (3,69)**			**68% of sample above x score**			
Positive Dimensions	T1 %	T2 %	Delta (T2-T1)	T1 score	T2 score	Delta (T2-T1)	D(%)
Empathy and congruence	81.16	93.93	12.77	3.96	4.3459	0.386	7.72
Unconditional acceptance	96	100	4.001	4.695	4.944	0.249	4.981
professional fulfilment	83.52	89.5	5.977	4.0559	4.318	0.262	5.241
Self confidence, dignity and meaning in spite dof advrsity and illness	80.59	95.38	14.79	4.0315	4.5	0.4684	9.369
close personal relationships and well-being	88.76	91.93	3.162	4.2597	4.4066	0.1469	2.938
	Cut-off (3,69)			**68% of sample under x score**			
Negative Dimensions	T1 %	T2 %	Delta (T2-T1)	T1 score	T2 score	Delta (T2-T1)	D(%)
avoidance mechanisms	13.67	11.45	-2.22	3.297	2.81	-0.487	-9.74
distance and impatience towards patient	0	0	0	2.1705	1.7464	-0.424	-8.48
fear of dependence, physical degradation and loss of control	53.17	35	-18.17	4.2372	3.7981	-0.439	-8.78
self-criticism regarding no time for family , friends and neaningful activities	28.89	18.12	-10.77	3.6592	3.3781	-0.281	-5.62
emotional exhaustion	28.76	13.61	-15.14	3.6141	3.276	-0.338	-6.76
depersonalization	1.788	0	-1.788	1.9477	1.7183	-0.229	-4.59

TABLE 17 - PERCENTAGE OF PARTICIPANTS IN OTHER UNITS ABOVE THE CUT-OFF POINT BEFORE AND AFTER INTERVENTION

The following figures show this information in graph format:



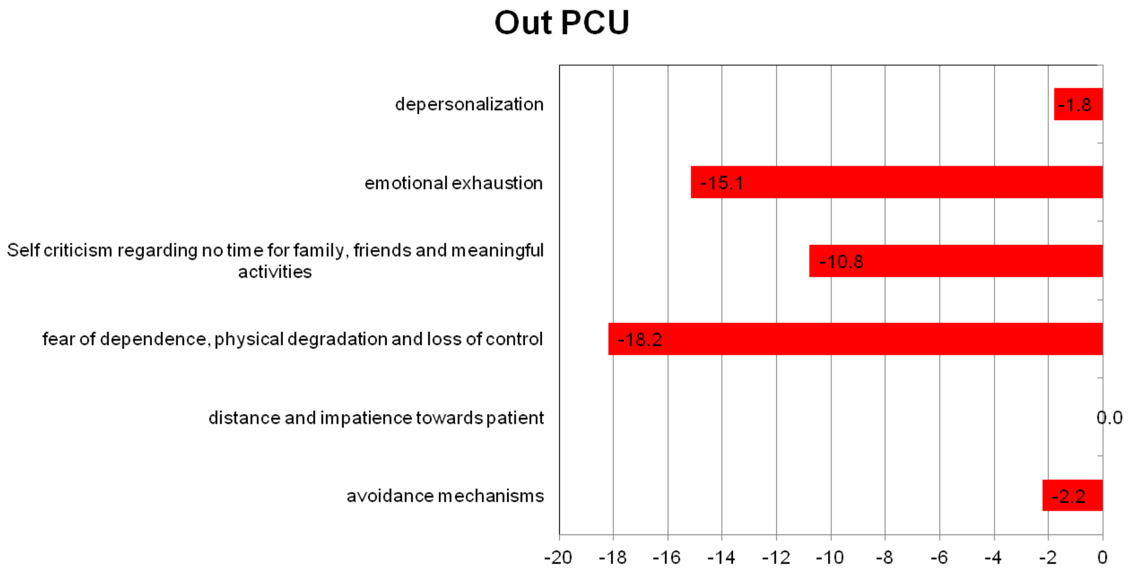


FIGURE 21 - GRAPHIC VISUALIZATION OF DIFFERENCE IN IMPROVEMENT OF HCWS IN OTHER UNITS IN RELATION TO % OF POPULATION ABOVE CUT-OFF POINT

These results showed that in the positive factors, HCWs in other units improved in all areas. In the negative factors, significant changes also occurred, especially in fear of dependence, physical degradation and loss of control: 53.17% of HCWs in other units were above the cut-off point, and at T2, only 35% were. Therefore there was a decrease in 18.17%. Significant improvements also occurred in emotional exhaustion and the time they gave to family friends and meaningful activities.

These results show differences in the response to training in the two groups. For instance, in the complete sample (n 150) , there was no significant difference in self criticism regarding no time for family and meaningful activities, but here, the percentage of HCWs above cut-off point before and after the training shows that HCWs in other units improved, whilst HCWs within PCUs became worse.

The greatest differences between these groups was in emotional exhaustion, their feelings for not having enough time for family and meaningful activities, self confidence in face of adversity and illness, perception of their capacity to empathize with the patient and feel congruent and unconditional acceptance. In general, HCWs in other units showed a greater change in scores following training than those within PC units.

However the scores for fear of dependence and physical degradation and avoidance mechanisms showed the converse as HCWs within PCUs improved to a greater extent than the HCWs not working within palliative care.

The following section shows the results of significant differences between in PCUs and in other units, using t-tests.

Comparison between Participants within PCUs and Other Units

Factor	mean T1	SD	mean T2	SD	Mean Tp	SD	t(148)	sig. (2-tailed)	mean difference	95% confidence interval (eta squared = 0.99)
Empathy and Congruence										
in PCU	4.19	0.67	4.38	0.71	3.92	0.71				
in other units	4.37	0.7	4.61	0.58	4.15	0.7				
comparison T1 in and out of PCU								ns		
comparison T2 in and out of PCU							-2.19	p=.03	-0.24	from -0.45 to -0.02
comparison Tp in and out of PCU							-2.05	p=.04	-0.24	from -0.46 to -0.008
Emotional exhaustion										
in PCU	2.94	0.75	2.88	0.81	3.01	0.77				
in other units	3.31	0.83	2.9	0.81	3.22	0.82				
comparison T1 in and out of PCU							-2.84	p=.005	-0.37	from -0.62 to -0.11
comparison T2 in and out of PCU								ns		
comparison Tp in and out of PCU								ns		

TABLE 18 - RESULTS OF SIGNIFICANT T-TESTS BETWEEN HCWS WITHIN PCUS AND IN OTHER UNITS

Empathy and congruence

In general, HCWs in other units saw themselves as having a better capacity to empathize with the patient and to be congruent with themselves than HCW's in palliative care units.

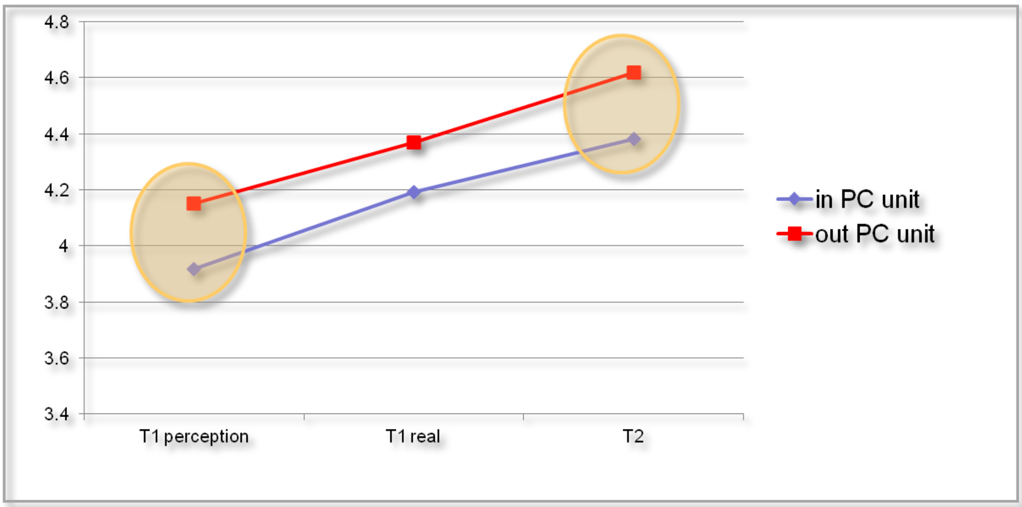


FIGURE 22 - EMPATHY AND CONGRUENCE WITHIN PCUS AND IN OTHER UNITS – MEANS

However, whereas before the training, there was no significant difference in empathy and congruence in these two groups, after the training, there was a significant difference in both T2 (p=.03) and T1p (p=.043). Health care workers in other units made more progress (5%) than HCWs within PCUs (3.8%) after training (in relation to T1). After the training, HCWs within PCUs perceived themselves as less empathetic and congruent than before the training (5,5%) in relation to T1 than HCWs in other units (4.3%)

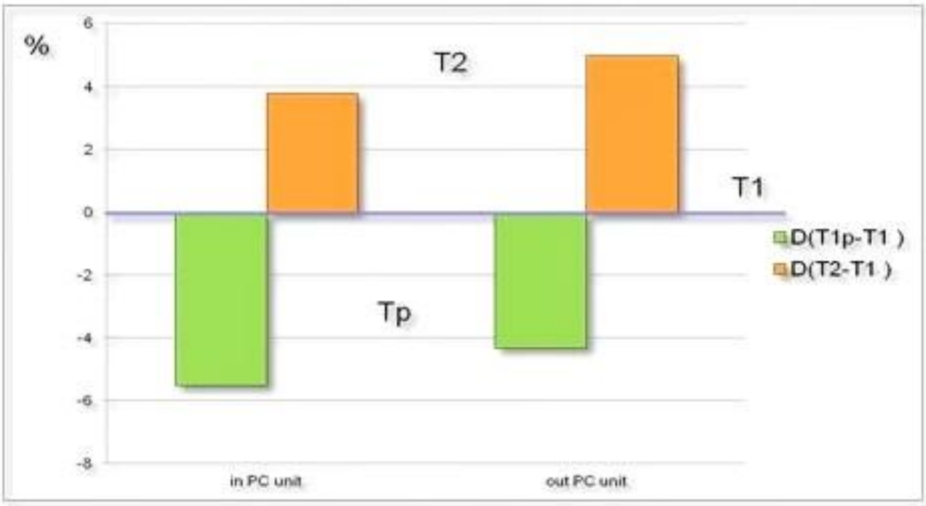


FIGURE 23 - EMPATHY AND CONGRUENCE WITHIN PCUS AND IN OTHER UNITS - PERCENTAGE

Emotional exhaustion

In relation to emotional exhaustion, although both groups were below the cut-off point, those working in non-palliative care settings suffered higher levels of emotional exhaustion. After the course, this difference was no longer significant.

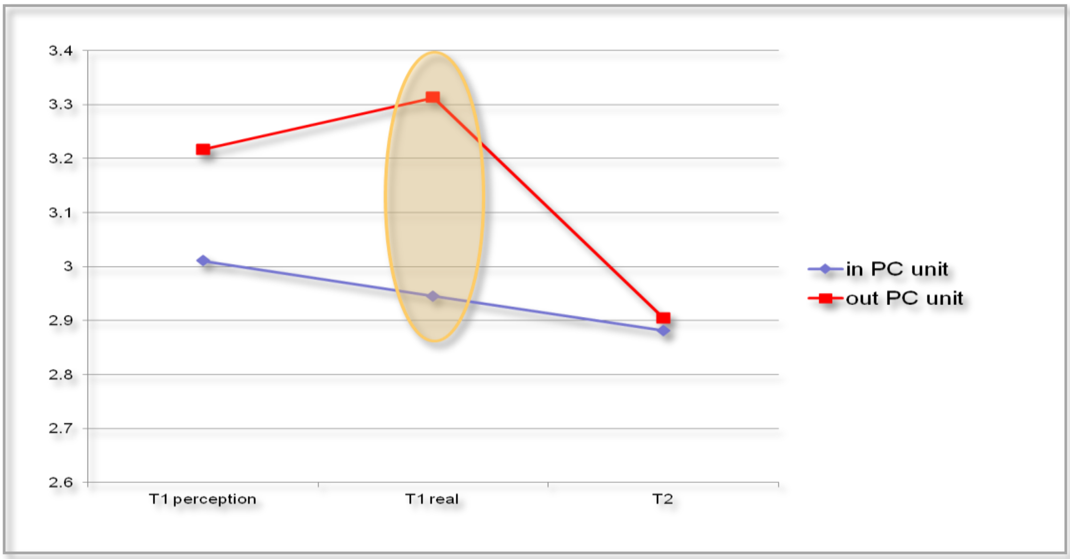


FIGURE 24 - EMOTIONAL EXHAUSTION WITHIN PCUS AND IN OTHER UNITS – MEANS

Health care workers in other units improved much more (8.1%) than HCWs within PCUs (1.3%), but they were also much more emotionally exhausted before the training.

After the training, however, HCWs in palliative care units changed their perception of how they thought they were before the training and concluded that they were more burnt out than they had originally thought (2%). HCWs in other units came to the conclusion that they were in fact better than they had originally thought (1.3%).

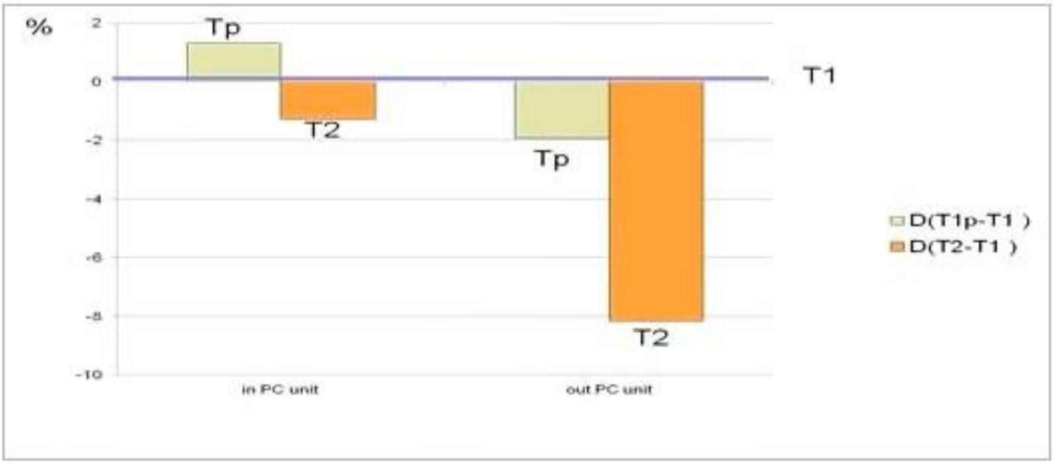
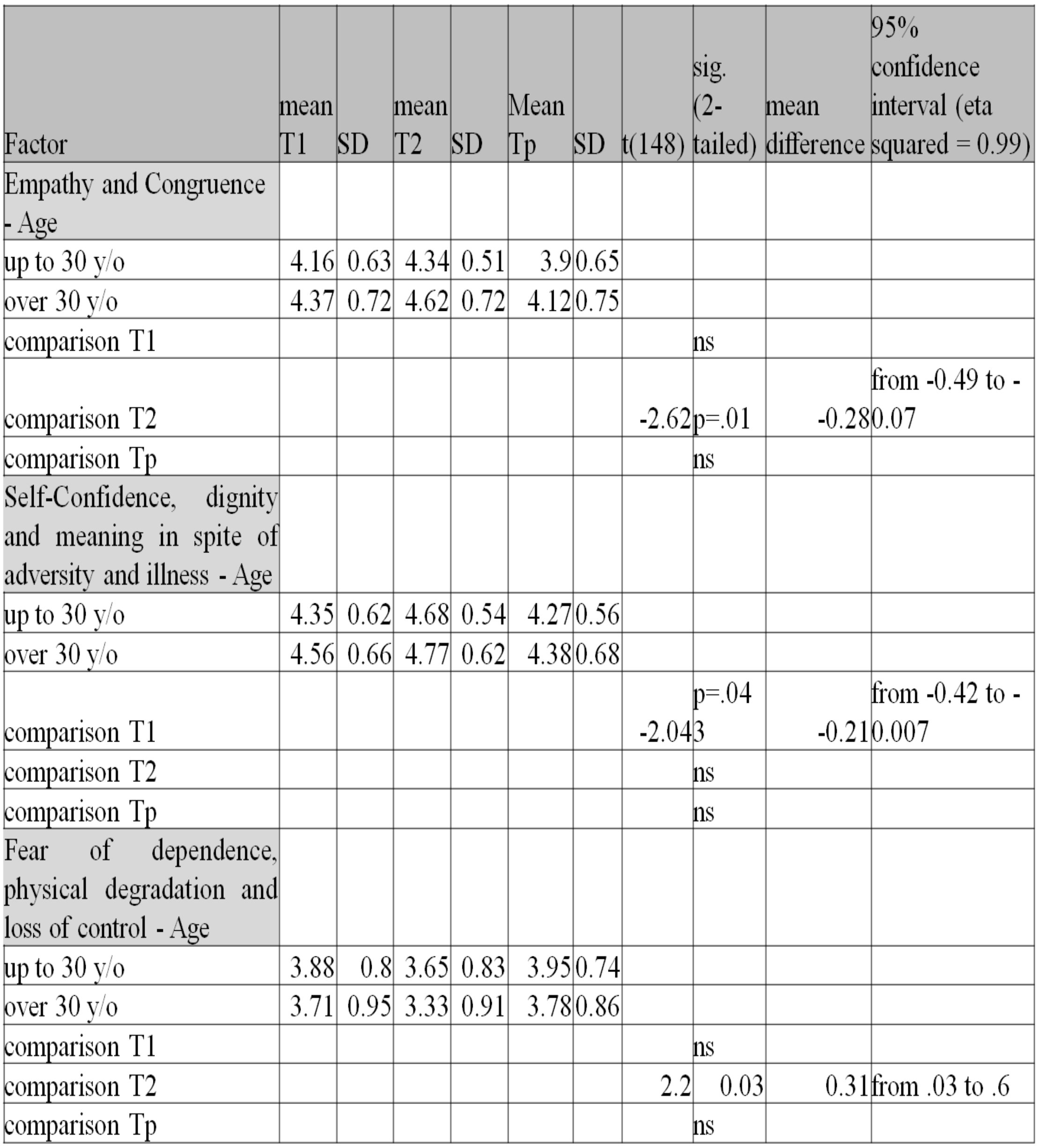


FIGURE 25 - EMOTIONAL EXHAUSTION WITHIN PCUS AND IN OTHER UNITS - PERCENTAGE

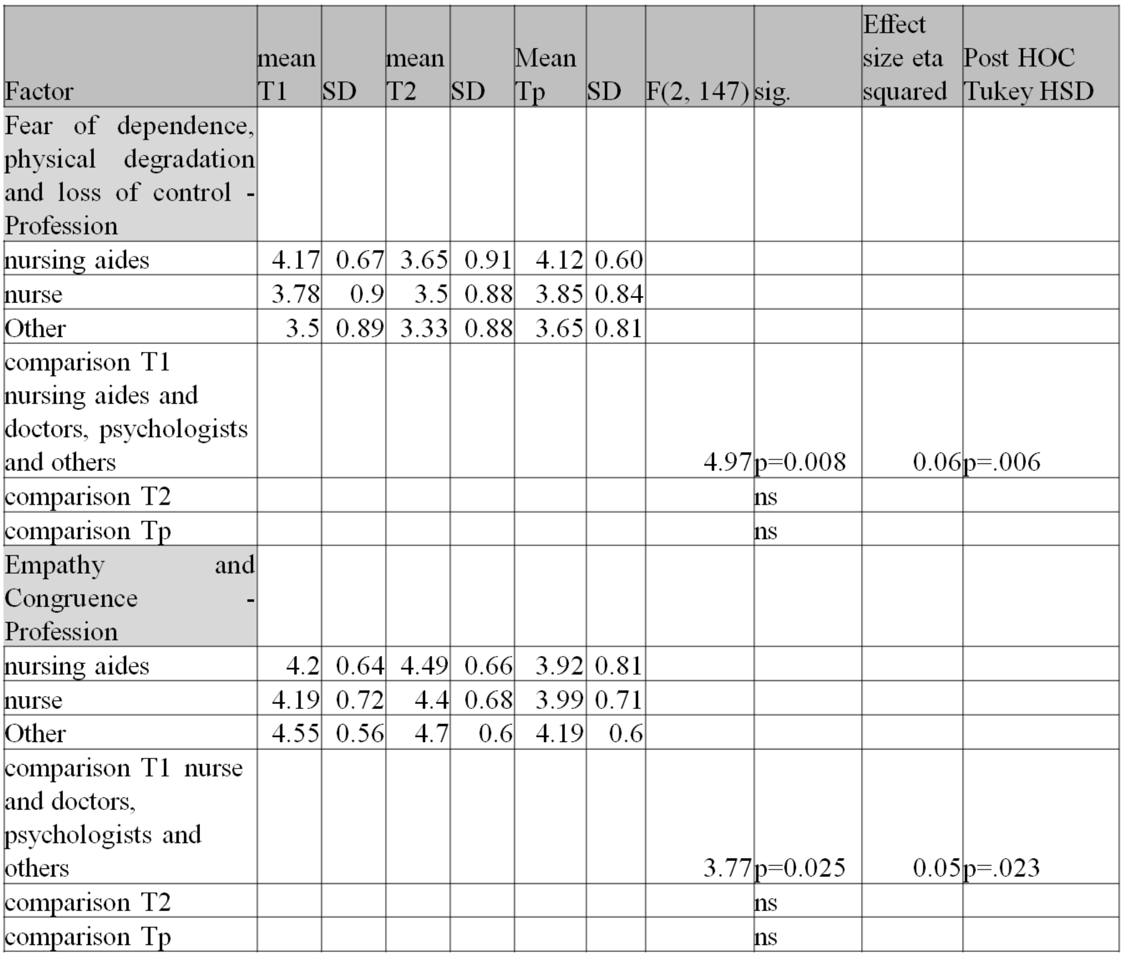
<u>Comparison of the Intervention Group (N = 150) by Age and Profession</u>

Table 19 shows the t-test results for significant differences between ages: over and under 30 years old, and table 20 shows the ANOVA results for significant differences between professions: nursing aides, nurses and doctors/psychologist and others.



Factor	mean T1	SD	mean T2	SD	Mean Tp	SD	t(148)	sig. (2-tailed)	mean difference	95% confidence interval (eta squared = 0.99)
Empathy and Congruence - Age										
up to 30 y/o	4.16	0.63	4.34	0.51	3.9	0.65				
over 30 y/o	4.37	0.72	4.62	0.72	4.12	0.75				
comparison T1								ns		
comparison T2							-2.62	p=.01	-0.28	from -0.49 to -0.07
comparison Tp								ns		
Self-Confidence, dignity and meaning in spite of adversity and illness - Age										
up to 30 y/o	4.35	0.62	4.68	0.54	4.27	0.56				
over 30 y/o	4.56	0.66	4.77	0.62	4.38	0.68				
comparison T1							-2.04	p=.043	-0.21	from -0.42 to -0.007
comparison T2								ns		
comparison Tp								ns		
Fear of dependence, physical degradation and loss of control - Age										
up to 30 y/o	3.88	0.8	3.65	0.83	3.95	0.74				
over 30 y/o	3.71	0.95	3.33	0.91	3.78	0.86				
comparison T1								ns		
comparison T2							2.2	0.03	0.31	from .03 to .6
comparison Tp								ns		

TABLE 19 - DIFFERENCES BETWEEN AGES - T-TEST



Factor	mean T1	SD	mean T2	SD	Mean Tp	SD	F(2, 147)	sig.	Effect size eta squared	Post HOC Tukey HSD
Fear of dependence, physical degradation and loss of control - Profession										
nursing aides	4.17	0.67	3.65	0.91	4.12	0.60				
nurse	3.78	0.9	3.5	0.88	3.85	0.84				
Other	3.5	0.89	3.33	0.88	3.65	0.81				
comparison T1 nursing aides and doctors, psychologists and others							4.97	p=0.008	0.06	p=.006
comparison T2								ns		
comparison Tp								ns		
Empathy and Congruence - Profession										
nursing aides	4.2	0.64	4.49	0.66	3.92	0.81				
nurse	4.19	0.72	4.4	0.68	3.99	0.71				
Other	4.55	0.56	4.7	0.6	4.19	0.6				
comparison T1 nurse and doctors, psychologists and others							3.77	p=0.025	0.05	p=.023
comparison T2								ns		
comparison Tp								ns		

TABLE 20 - DIFFERENCES IN PROFESSION – ANOVA

Age

The sample was divided into two groups: those up to 30 years old (73 participants), and those over 30 years old (77 participants).

Empathy and congruence

The following figure shows that the older health care workers perceived themselves as more empathetic and congruent, and after the training, this difference became significant ($p< .01$).

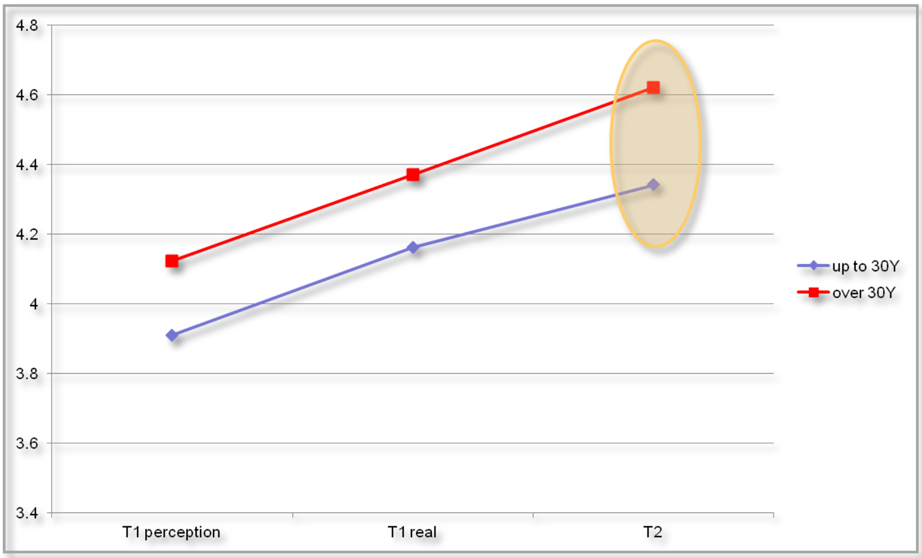


FIGURE 26 - EMPATHY AND CONGRUENCE: MEANS T1P, T1 AND T2 - AGE

The older HCWs were also able to improve their attitudes of empathy and personal congruence more than the younger ones. After the training, both groups realised they were less empathetic before the training than they originally thought they were.

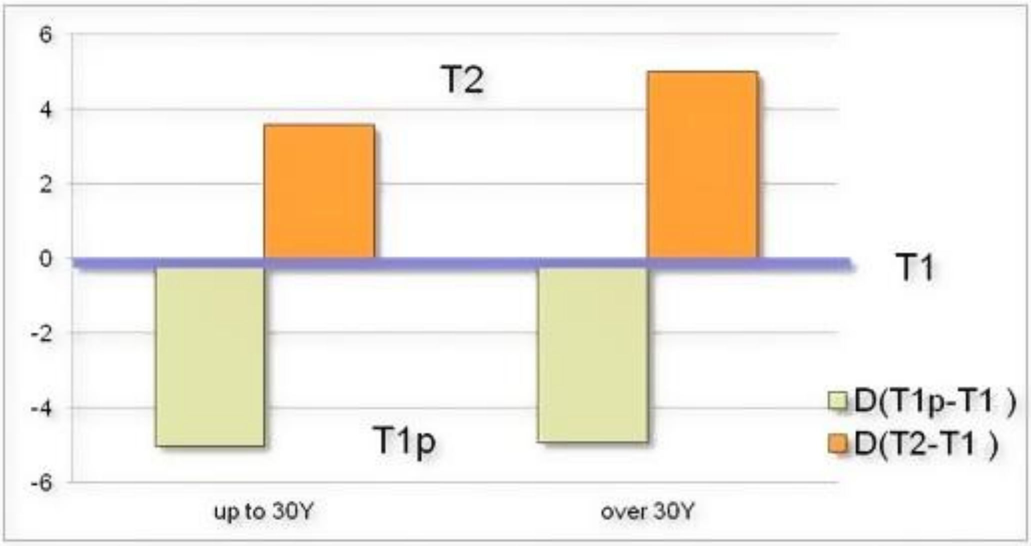


FIGURE 27 - EMPATHY AND CONGRUENCE: T1P AND T2 IN RELATION TO T1 - AGE

Self-confidence, dignity and meaning in spite of adversity and illness

The following figure shows that being older has a positive influence on the person's self confidence and capacity to maintain a sense of dignity and meaning in life when faced with the possibility of a life threatening disease: there was a significant difference in self-confidence in the face of adversity and illness before the course (p<.043) in HCWs over age 30.

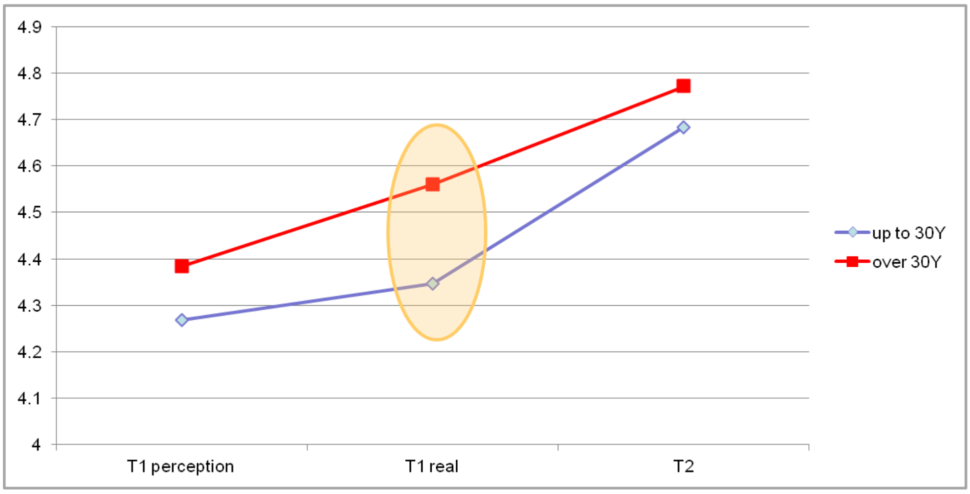


FIGURE 28 - SELF-CONFIDENCE, DIGNITY AND MEANING WHEN FACED WITH ADVERITY AND ILLNESS, T1P, T1 AND T2 - AGE

After the course, this difference was no longer significant because the group under 30 years old had improved in self-confidence (6.7%) than the over 30 (4.2%). However, Health Care Workers over 30 perceived themselves as having less confidence before the training (3.5%) in relation to T1 than HCWs up to 30 (1.6%).

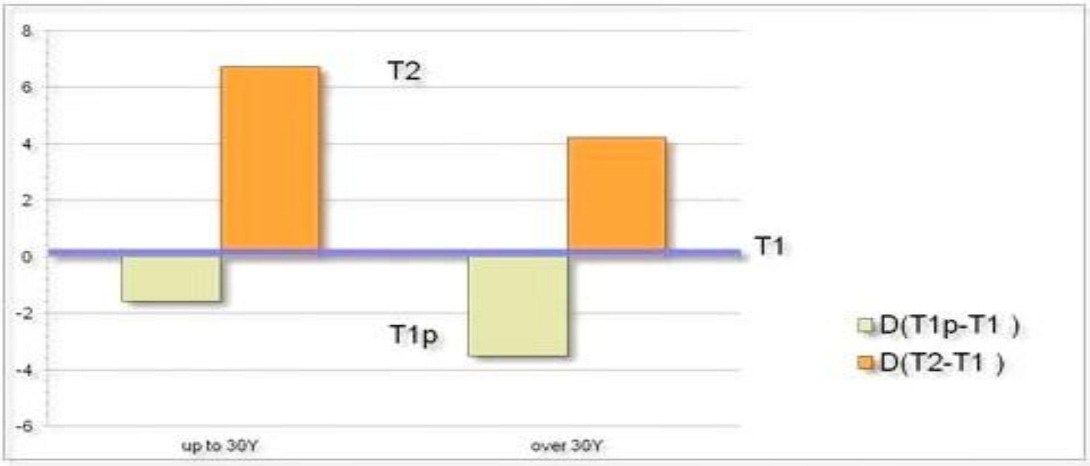


FIGURE 29 - SELF-CONFIDENCE, DIGNITY AND MEANING WHEN FACED WITH ADVERSITY AND ILLNESS –T1P AND T2 IN RELATION TO T1 - AGE

Fear of dependence, physical degradation and loss of control

The results for fear of dependence and physical degradation were the highest among all of the negative factors: 51.33 % of HCWs scored their distress above the cut-off point at T1, and this was reduced to 32 percent at T2. Following the course, levels remained high, although the mean result was reduced to just below the cut-off point. However, age seems to play an important role here. The following figure shows that the younger health care workers are more fearful about the thought of their own possibility to be dependent on others, to experience physical degradation with illness and to lose control over their lives than older HCW's: before the course, although HCWs under 30 had higher scores, there was no significant difference between the two groups (the under-30 group and the over-30 group). After the course, there was evidence of a significant difference. HCWs over 30 appeared less afraid of suffering and physical degradation than those under 30.

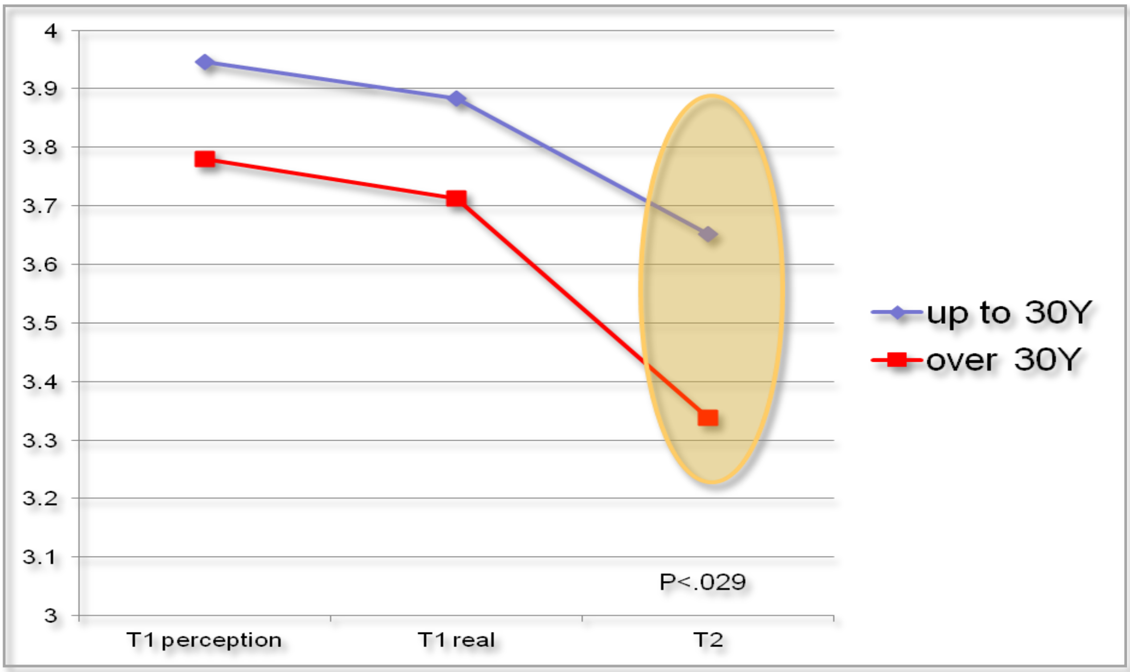


FIGURE 30 - FEAR OF DEPENDENCE, PHYSICAL DEGRADATION AND LOSS OF CONTROL T1P, T1 AND T2

Those under 30 made some progress with the training (4.6%), but not as much as the older HCWs (7.5%). The difference between the two groups became significant due to the improved scores of the older group after the training ($p < .03$), meaning they felt less fearful.

FIGURE 31 - FEAR OF DEPENDENCE, PHYSICAL DEGRADATION AND LOSS OF CONTROL - AGE

Profession

This will be analysed as group 1 (nursing aides), group 2 (nurses), and group 3 (all other professions, but consisting mainly of doctors and psychologists) using one-way between-groups ANOVA. There was a statistically significant change in the following areas:

Fear of dependence, physical degradation and loss of control

Before the training there was a significant difference in scores of the 3 groups of professions. The mean score for group 1 (nursing aides) was significantly different from group 3 (doctors, psychologists and others). Group 2 (nurses) did not differ significantly from either group 1 or 3. After the training, there was no significant difference between the different professions; doctors, psychologists, others and nurses.

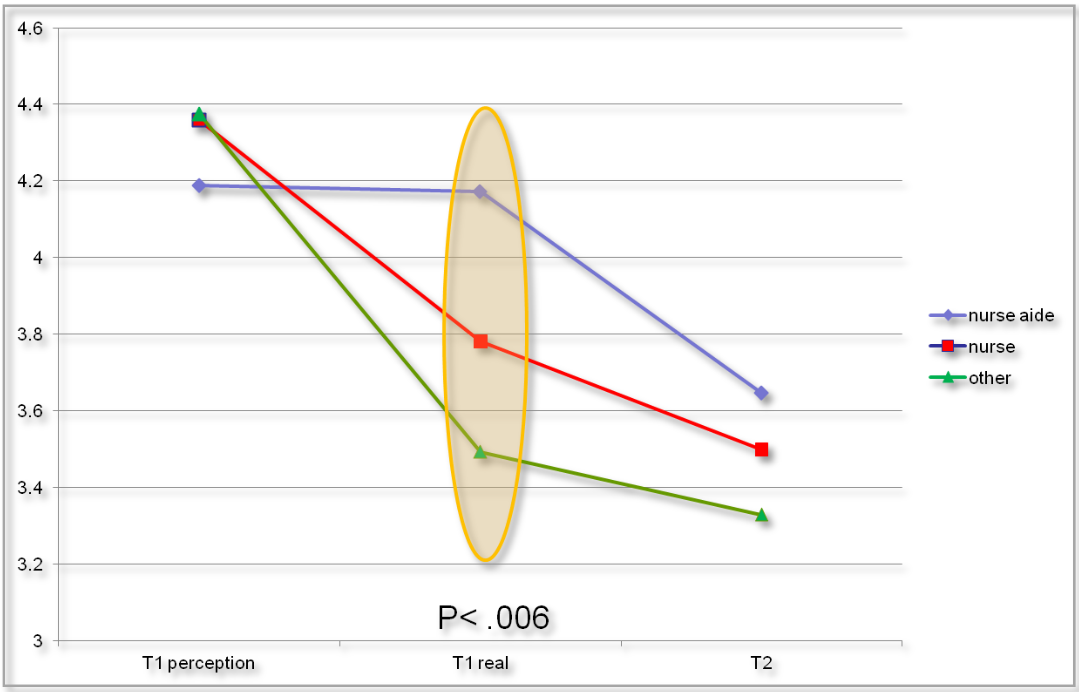


FIGURE 32 - FEAR OF DEPENDENCE, PHYSICAL DEGRADATION AND LOSS OF CONTROL - PROFESSION T1P, T1 AND T2

However, of the 3 groups, nursing aides felt less fear after the training (10.5%). After the training, the perception of doctors and psychologists of how they were before changed the most (17.6% more fearful), then nurses (11.6%). The perception of nursing aides hardly changed at all (0.3%).

FIGURE 33 - FEAR OF DEPENDENCE, PHYSICAL DEGRADATION AND LOSS OF CONTROL T1P AND T2 IN RELATION TO T1 - PROFESSION

Empathy and congruence

Before the training there was a significant difference in scores of the 3 groups of professions. The mean score for group 2 (nurses) was significantly different from group 3 (doctors, psychologists and others). Group 1 (nursing aides) did not differ significantly from either group 2 or 3. After the training, there was no significant difference between the different professions.

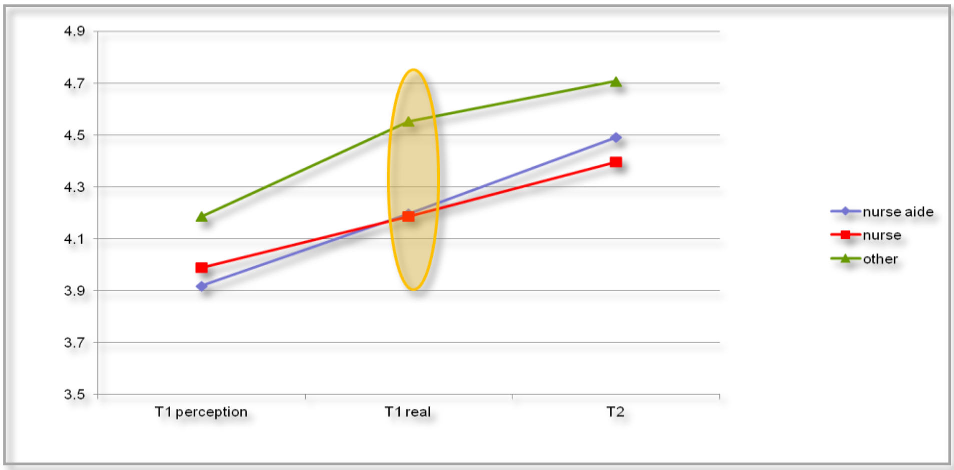


FIGURE 34 - EMPATHY AND CONGRUENCE T1P, T1, T2 - PROFESSION

After the training, nursing aides improved the most (5.9%), followed by nurses (4.2%), and finally doctors and nurses (3.1%). After the training, change in perception of performance before the training changed the most in doctors/psychologists (7.3%), followed by nursing aides (5.5%), then nurses (4%), meaning they felt more empathetic and congruent.

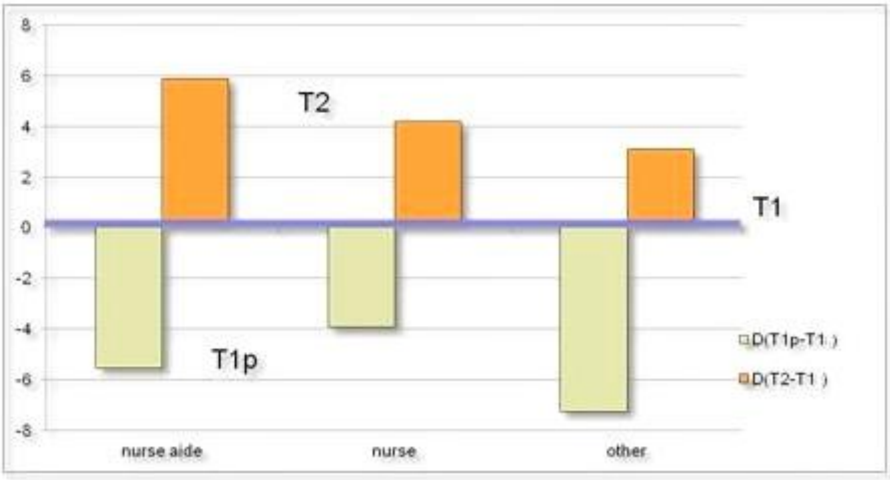


FIGURE 35 - EMPATHY AND CONGRUENCE T1P AND T2 IN RELATION TO T1 - PROFESSION

Section Summary

These results show that HCWs who worked in PCUs made the most improvement in the area of “fear of dependence, physical degradation and loss of control”, and for those working in other units, it was in the areas of “self-confidence, dignity and meaning in life in spite of adversity and illness”, “empathy and congruence”, “emotional exhaustion”, and also of “fear of dependence, physical degradation and loss of control”. Statistically significant differences between HCWs within PCUs and in other units were found in the areas of empathy and congruence and emotional exhaustion, where HCWs in other units in general made the most improvement.

When the age of participants was considered, there was a statistically significant difference between HCWs under and over 30 years old before the training, and HCWs over 30 years scored higher in “self confidence, dignity and meaning in life in spite of adversity and illness” and after the training, this difference disappeared. In “empathy and congruence”, there was no significant difference before the training, but after the training, more HCWs over 30 improved their scores than those under 30. In “fear of dependence, physical degradation and loss of control”, although there was a significant improvement in both age groups, more HCWs over 30 years old improved their scores than those under 30 years old.

When the profession of the participants was considered, doctors and psychologists had significantly higher levels in their capacity to empathize with patients and feel congruent in the relationship in comparison to nurses, but after the training, this difference disappeared. Before the training, nursing aides had significantly higher levels of “fear of dependence, physical degradation and loss of control” in comparison to doctors and psychologists, and after the training, this difference disappeared.

4.2.4 EFFECT OF INTERVENTION ON BURNOUT

As explained in the methodology section, burnout was assessed using a questionnaire that was devised specifically to measure burnout in health care workers who care for patients with a terminal condition. It was composed of questions related to burnout in general, using questions from the Maslach Burnout Inventory (Maslach, et al., 1986) and the Jerabek burnout test (Jerabek, 2001) and questions related to burnout in end of life care, that were devised specifically by the author, following a survey carried out with health care workers who cared for patients with a terminal condition. The resultant questionnaire measuring burnout consisted of the core items analysed and compared in the previous sections.

The results show that overall levels of burnout as measured by this questionnaire were relatively low, however this was not the general impression received orally from participants during the 29 interventions. For this reason, burnout was analyzed in greater detail. The items related to general burnout were separated from those related to death and dying, (see following table) to understand whether burnout was present, but for different reasons:

EE21	Dealing psychologically with terminally ill patients makes me feel insecure and anxious
EE 10	I feel helpless when faced with the patient’s fragility
EE 25	I am emotionally disturbed by the death of so many patients
EE 28	The relationship with the patient’s family wears me out
EE 13	I am frustrated because I cannot find the time to have a quality relationship with the patient
EE 35	I feel stressed due to lack of debate and support within the team, with regard to our difficulties
EE 38	I ask myself many times if I could have “done more” and this makes me feel anxious
D 30	I give more importance to the technical part of my work than to the human part
D 34	I give a lot of importance to treating the illness, but do not have patience for the psychological and spiritual caring of the patient
PF 9	I feel fulfilled at work because I manage to find time to just “be” with the patient or their family
PF 33	I have moments of sharing with the patients, with no need to hide my feelings
PF 11	My work allows me to value life more
PF 39	I manage to find time in my work to talk to patients and to help them find meaning in their lives
PF 40	I often contribute towards giving my patients quality of life, comfort and dignity at the end of their life

EE = Emotional Exhaustion; D = Depersonalization; PF = Professional Fulfilment – followed by the nr of the item in the questionnaire.

TABLE 21 - ITEMS FROM BURNOUT QUESTIONNAIRE RELATED SPECIFICALLY TO DEATH AND DYING

The mean scores were calculated for the total group and also differentiating between HCWs working within PCUs and in other units.

The following tables 22 and 23 show the mean scores of Burnout with and without questions devised by the author for HCWs who care for patients with a terminal condition:

Name of Questionnaire	Factors derived from factor analysis using PCA	T1	SD	T2	SD
Burnout specific for HCW who care for patients with a terminal condition	Emotional exhaustion	3.50	.87348	2.65	.94346
	Professional fulfilment	4.4	.81918	4.52	.61861
	Depersonalization	1.7	.80848	1.62	.60748

TABLE 22 - MEANS OF BURNOUT SPECIFIC FOR HCWS WHO CARE FOR PATIENTS WITH A TERMINAL CONDITION N= 150

Name of Questionnaire	Factors derived from factor analysis using PCA	T1	SD
Normal burnout	Emotional exhaustion	2.7	.88449
	Professional fulfilment	4.4	.61707
	Depersonalization	1.8	.67055

TABLE 23 - MEANS OF BURNOUT WITHOUT QUESTIONS SPECIFIC FOR HCWS WHO CARE FOR PATIENTS WITH A TERMINAL CONDITION N= 150

These results show that when we separate the questions designed by Maslach (Maslach, et al., 1986) and Jerabek, (Jerabek, 2001) from the ones designed by the author specifically for HCWs who care for patients with a terminal condition, the mean scores of burnout in both cases are below the cut-off point where emotional exhaustion is concerned (if their scores were above the cut-off point, they would be considered to be suffering from emotional exhaustion). However, t-tests between the two groups of items show that there is a significant difference between the two sub-factors (p<.005), in that the specific items for burnout in end of life care are much higher, (M=3.5 - only 0.19 point below the cut-off level), as seen in table 24:

Burnout factors: questions by Carol Gouveia Melo (CGM) and Maslach and Jerabek (CM+J)	Mean	N	Std. Deviation	Std. Error Mean	Sig (2-tailed)
T1 emotional exhaustion CGM	3.5	150	0.873	0.071	p< .005
T1 emotional exhaustion CM + J	2.7	150	0.884	0.072	
T1 depersonalization CGM	1.69	150	0.808	0.066	p< .023
T1 depersonalization CM + J	1.84	150	0.671	0.055	
T1 professional fulfilment CGM	4.4	150	0.819	0.067	NS
T1 professional fulfilment CM + J	4.37	150	0.617	0.05	

TABLE 24 - T-TEST BURNOUT - COMPARISON OF ITEMS SPECIFIC FOR HCWS WHO CARE FOR THE PATIENTS WITH A TERMINAL CONDITION AND OTHER ITEMS

In order to understand if there was any significance to these results, assessment of burnout in end-of life care was also performed in HCWs working within PCUs and in other units showing that emotional exhaustion in HCWs caring for the dying in other units was above the cut-off point meaning that they were suffering from emotional exhaustion: (table 25),

Burnout	Mean within PCUs T1	Mean in other units T1	Mean within PCUs T2	Mean in other units T2
T1 Emotional Exhaustion CGM	3.3	3.8	2.63	2.69
T1 Depersonalization CGM	1.7	1.7	1.67	1.56
T1 Professional fulfilment CGM	4.4	4.4	4.54	4.49

TABLE 25 - BURNOUT WITHIN PCUS AND IN OTHER UNITS USING ONLY ITEMS SPECIFIC FOR HCWS WHO CARE FOR PATIENTS WITH A TERMINAL CONDITION

A further analysis of these results may show the factors involved in the emotional exhaustion of HCWs who care for patients with a terminal condition. Consideration of the individual items of emotional exhaustion specific for end of life care show differing results for HCWs within PCUs and in other units:

Question related to emotional exhaustion	All HCWs	HCWs within PCUs	HCWs in other units
I ask myself many times if I could have "done more" and this makes me feel anxious	3.86	3.49	4.34
I feel that I work too hard in my profession	3.82	3.74	3.92
I feel helpless when faced with the patient's fragility	3.66	3.69	3.62
I am emotionally disturbed by the death of so many patients	3.54	3.13	4.09
I feel stressed due to the lack of debate and support within the team, with regard to our difficulties	3.53	3.19	3.98

TABLE 26 - COMPARISON OF ITEMS RELATED TO EMOTIONAL EXHAUSTION, WITHIN PCUS AND IN OTHER UNITS

It can be postulated that the causes of the most exhaustion in HCWs within PCUs is work overload, as seen in the responses to the second question shown in table 26, ("I feel that I work too hard in my profession") followed by feelings of helplessness. However, for HCWs working in other units, emotional exhaustion seems to be more related to the feeling they could have "done more", followed by too many deaths. Overall, HCWs in other units had higher scores in emotional exhaustion than HCWs within PCUs.

After the intervention, HCWs in other units were shown to have improved scores in relation to those working within PCUs: T-tests were performed of these specific items, between T1 and T2, with the following results (table 27):

Question related to emotional exhaustion T1/T2	HCWs within PCUs	HCWs in other units
I ask myself many times if I could have "done more" and this makes me feel anxious	Ns	P<0.001
I feel that I work too hard in my profession	Ns	Ns
I feel helpless when faced with the patient's fragility	P<0.032	P<0.008
I am emotionally disturbed by the death of so many patients	Ns	P<0.001
I feel stressed due to the lack of debate and support within the team, with regard to our difficulties	Ns	P<0.019

TABLE 27 - T-TEST OF RESULTS OF ITEMS RELATED TO EMOTIONAL EXHAUSTION WITHIN PCUS AND IN OTHER UNITS AT T1 AND T2

Overall, HCWs within PCUs did not make any significant changes in scores in this specific area except for “feeling helpless when faced with the patient’s fragility”, whereas HCWs in other units made significant changes in almost all areas. Work overload was an area where no changes were made in both groups.

When separating HCWs under and over 30 year old, the results show differences in causes of emotional exhaustion: HCWs under 30 scored at higher levels of burnout as they seem to find the issues relating to not finding the time to have a quality relationship with the patient stressful, but do not mention work overload as the main stressor, whereas for HCWs over 30, work overload is the main factor, followed by frustration for not being able to spend quality time with patients.

T1:

under 30 y/o	N	Mean	Std. Deviation
I am frustrated because I cannot find the time to have a quality relationship with the patient	73	4.19	1.48752
I ask myself many times if I could have "done more" and this makes me feel anxious	73	3.88	1.48085
I feel helpless when faced with the patient's fragility.	73	3.86	1.39757
over 30 y/o			
I feel that I work too hard in my profession.	77	4.05	1.27626
I am frustrated because I cannot find the time to have a quality relationship with the patient.	77	3.95	1.54661
I ask myself many times if I could have "done more" and this makes me feel anxious.	77	3.84	1.34815

After the training, both groups mentioned frustration due to lack of time to have a quality relationship with patients as the main stressor:

T2:

under 30 y/o	N	Mean	Std. Deviation
I am frustrated because I cannot find the time to have a quality relationship with the patient	73	3.87	1.46191
I ask myself many times if I could have "done more" and this makes me feel anxious	73	3.60	1.43838
over 30 y/o			
I am frustrated because I cannot find the time to have a quality relationship with the patient.	77	3.78	1.65134
I feel that I work too hard in my profession.	77	3.75	1.54858

TABLE 28 - ITEMS RELATED TO EMOTIONAL EXHAUSTION OVER AND UNDER 30 Y/O

There were no significant differences of emotional exhaustion between professions, although auxiliary nurses, who had no training, scored the highest:

T1 emotional exhaustion	N	Mean	Std. Deviation
Auxiliary nurse	30	3.2089	.68632
Nurse	87	3.1054	.86199
Other	33	3.0061	.75449
Total	150	3.1042	.80445
T2 emotional exhaustion	N	Mean	Std. Deviation
Auxiliary nurse	30	3.0477	.67335
Nurse	87	2.9252	.89658
Other	33	2.6607	.64045
Total	150	2.8915	.81097

TABLE 29 - ITEMS RELATED TO EMOTIONAL EXHAUSTION BY PROFESSION

4.2.5 EFFECT OF INTERVENTION ON FEARS RELATED TO DEATH AND DYING/DEATH ANXIETY

The literature review showed that death anxiety in HCWs was related to a fear of unfulfilled personal relationships and meaning in life, fear of the unknown, of physical change and dependency on others and unresolved grief. In order to see if death anxiety was manifested in the same way in Portugal, the individual items related to the fear of death and dying, where health care workers scored over the cut-off point were highlighted. Scores were differentiated between HCWs within PCUs and in other units (table 30):

Fears related to death and dying and avoidance mechanisms (in PCU)	Mean	Fears related to death and dying and avoidance mechanisms (outside PCU)	Mean
If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them.	4.6941	If I have to die, may it be quick.	4.6308
I feel the need to be informed of everything that surrounds me.	4.4118	I feel the need to be informed of everything that surrounds me.	4.4308
I am not at ease until I have everything "under control".	4.3529	If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them.	4.3231
I am afraid of being a burden to others.	4.3412	I am afraid of being a burden to others.	4.2308
If I have to die, may it be quick.	4.3059	I am not at ease until I have everything "under control".	4.2000
I do everything I can to avoid any difficulties or instabilities in my life.	4.2000	If I cannot be an active and independent person, my life would lose all meaning.	3.9846
There are times when my outward response to them is quite different from the way I feel underneath	3.9412	There are times when my outward response to them is quite different from the way I feel underneath	4.0154
If I become ill, I would rather die than become dependent on others.	3.9529	I often do not show my appreciation to friends and family, and then regret it.	3.9385
If I cannot be an active and independent person, my life would lose all meaning.	3.8706	I do everything I can to avoid any difficulties or instabilities in my life.	3.8469
If I only had one more year to live, there would not be many things I would stop doing because they are a waste of time.	3.7647	I still need to identify what I still want to do in life before dying.	3.8154
I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life.	3.7059	If I become ill, I would rather die than become dependent on others.	3.8154
Sometimes they seem to me a more worthwhile person than they do at other times.	3.4471	If I only had one more year to live, there would not be many things I would stop doing because they are a waste of time.	3.7191
I often do not show my appreciation to friends and family, and then regret it.	3.5647	The time of dying has no value. It is best to die quickly to end the suffering.	3.7077
I still need to identify what I still want to do in life before dying.	3.5176	I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life.	3.6722
		I normally feel quite unconfident when faced with the unknown.	3.6000
		Sometimes they seem to me a more worthwhile person than they do at other times.	3.6769

TABLE 30 - ITEMS RELATED TO FEAR OF DEATH AND DYING WITHIN PCUS AND IN OTHER UNITS

It would seem that Portuguese HCWs also have the same manifestation of death anxiety to that reported in the literature. Results are similar between the two groups, but in HCWs within

PCUs, the number one fear is related to personal relationships, whereas in HCWs working in other units, the number one fear is related to the process of death: “If I have to die, may it be quick”.

Further analysis of the items shows that this fear seems to be related to the unknown, to being a burden on others and of suffering and pain. HCWs in other units showed two more fears above the cut-off point than HCWs within PCUs: “The time of dying has no value. It is best to die quickly to end the suffering” and “I normally feel quite unconfident when faced with the unknown”.

Comparison of results after the training showed that in general, where results were significant, HCWs in other units made more improvement, with the exception of being afraid of being a burden to others. In this item, HCWs who worked within PCUs showed less fear after the intervention. All items improved after the intervention with the exception of “I often do not show my appreciation to friends and family, and then regret it” which worsened in HCWs within PCUs (table 31):

Fears related to death and dying and avoidance mechanisms T1/T2	in PC	in other units
If I have to die, may it be quick.	ns	p<.004
If I were to die tomorrow, I would need to talk to some people close to me to feel up to date with them.	ns	Ns
I normally feel quite unconfident when faced with the unknown.	ns	Ns
I am not at ease until I have everything "under control".	p<.025	p<.002
If I cannot be an active and independent person, my life would lose all meaning.	p<.007	p<.006
The time of dying has no value. It is best to die quickly to end the suffering.	p<.006	p<.005
I often do not show my appreciation to friends and family and then regret it.	p<.05 worse	Ns
I feel the need to be informed of everything that surrounds me.	ns	Ns
If I become ill, I would rather die than become dependent on others.	p<.01	p<.016
I still need to identify what I still want to do in life before dying.	ns	p<.014
I am afraid of being a burden to others.	p<.05 worse	Ns
If I only had one more year to live, there would not be many things I would stop doing because they are a waste of time.	ns	Ns
I do everything I can to avoid any difficulties or instabilities in my life.	ns	Ns
I do not regularly make a balance of my life to avoid losing sight of what is important to me and gives meaning to my life.	ns	p<.008
Sometimes they seem to me a more worthwhile person than they do at other times.	ns	Ns
There are times when my outward response to them is quite different from the way I feel underneath	ns	Ns

TABLE 31 - T-TEST FEARS RELATED TO DEATH AND DYING AND AVOIDANCE MECHANISMS T1/T2

The results also show how HCWs may avoid some of these issues. The highest scores for the avoidance mechanisms are as shown in table 32:

Avoidance Mechanisms (in PCUs)	Mean	Avoidance Mechanisms (outside PCUs)	Mean
There are times when my outward response to them is quite different from the way I feel underneath	3.94	There are times when my outward response to them is quite different from the way I feel underneath	4.02
Sometimes they seem to me a more worthwhile person than they do at other times.	3.45	Sometimes they seem to me a more worthwhile person than they do at other times.	3.68
Sometimes I am not at all comfortable with them, but we go on, outwardly ignoring it.	3.38	Sometimes I am not at all comfortable with them, but we go on, outwardly ignoring it.	3.38
At the time I don't realize how touchy or sensitive they are about some of the things we discuss	3.24	At the time I don't realize how touchy or sensitive they are about some of the things we discuss	3.24
I don't show my inner impressions and feelings with them	3.21	I don't show my inner impressions and feelings with them	3.18
It bothers me when they try to ask or talk about certain things	3.20	It bothers me when they try to ask or talk about certain things	2.97

TABLE 32 - MOST COMMONLY USED AVOIDANCE MECHANISMS WITHIN PCUS AND IN OTHER UNITS

These results show that the avoidance mechanisms used within PCUs and in other units are basically the same. The only item related to avoidance mechanisms that scored above the cut-off point was “There are times when my outward response to them is quite different from the way I feel underneath”, showing that they may be unable to feel congruent within the relationship and put on a protective front, hiding their real feelings. Although the items were not above the cut-off point, most of them expressed the same feeling, but in different words.

4.2.6 THE RELATIONSHIP BETWEEN BURNOUT, PERSONAL WELL-BEING AND HELPING RELATIONSHIP SKILLS

The relationships between burnout, personal well-being and attitudes within the helping relationship were investigated using Pearson product-moment correlation coefficient. Analyses using Q-Q Plots were performed to ensure there was no violation of the assumptions of normality, linearity and homoscedasticity. The results are presented in the following tables. Correlations with an r value > .500 can be considered to be strong (highlighted in yellow), r = .30

to .49 medium and r = .10 to .29, weak. All correlations were significant at level p<.05 and the majority were significant at level p<.001).

Factors	Empathy and congruence	Unconditional acceptance	Avoidance mechanisms	Distance and impatience towards patient	Emotional exhaustion	Professional fulfilment	Deper-sonalisation	Self-confidence, dignity and meaning when faced with adversity and illness	Close relationships and personal well-being	Fear of dependence, physical degradation and loss of control	Self criticism regarding time for family, friends and meaningful activities
Empathy and congruence	1.000										
Unconditional acceptance	,587**	1.000									
	.000										
Avoidance mechanisms	-,338**	-,291**	1.000								
	.000	.000									
Distance and impatience towards patient	-,294**	-,575**	,548**	1.000							
	.000	.000	.000								
Emotional exhaustion	-,298**	-,325**	,558**	,442**	1.000						
	.000	.000	.000	.000							
Professional fulfilment	,671**	,580**	-,327**	-,344**	-,405**	1.000					
	.000	.000	.000	.000	.000						
Depersonalisation	-,274**	-,302**	,509**	,450**	,533**	-,354**	1.000				
	.001	.000	.000	.000	.000	.000					

Factors	Empathy and congruence	Unconditional acceptance	Avoidance mechanisms	Distance and impatience towards patient	Emotional exhaustion	Professional fulfilment	Deper-sonalisation	Self-confidence, dignity and meaning when faced with adversity and illness	Close relationships and personal well-being	Fear of dependence, physical degradation and loss of control	Self criticism regarding time for family, friends and meaningful activities
Self-confidence, dignity and meaning when faced with adversity and illness	,467**	,510**	-,221**	-,250**	-,399**	,584**	-,260**	1.000			
	.000	.000	.007	.002	.000	.000	.001				
Close relationships and personal well-being	,435**	,440**	-,161*	NS	-,344**	,615**	-,279**	,601**	1.000		
	.000	.000	.049		.000	.000	.001	.000			
Fear of dependence, physical degradation and loss of control	NS	NS	,347**	NS	,346**	NS	,257**	-,318**	NS	1.000	
			.000		.000		.001	.000			
Self criticism regarding time for family, friends and meaningful activities	NS	-,204*	,479**	,333**	,516**	-,204*	,494**	-,268**	-,269**	,406**	1.000
		.012	.000	.000	.000	.012	.000	.001	.001	.000	

TABLE 33 - CORRELATIONS BETWEEN THE DIFFERENT FACTORS BEFORE THE INTERVENTION

The results from after the intervention are shown in table 34: Correlations that became stronger after the training are highlighted in blue:

Factors	Empathy and congruence	Unconditional acceptance	Avoidance mechanisms	Distance and impatience towards the patient	Emotional exhaustion	Professional fulfilment	Depersonalization	Self confidence, dignity and meaning when faced with adversity	Close relationships and personal well-being	Fear of dependence, physical degradation and loss of control	Self criticism regarding time for family, friends and meaningful activities
Empathy and congruence	1.000										
Unconditional acceptance	,601**	1.000									
	.000										
Avoidance mechanisms	-,391**	-,291**	1.000								
	.000	.000									
Distance and impatience towards the patient	-,371**	-,531**	,529**	1.000							
	.000	.000	.000								
Emotional exhaustion	-,372**	-,313**	,398**	,274**	1.000						
	.000	.000	.000	.001							
Professional fulfilment	,642**	,466**	-,320**	-,348**	-,409**	1.000					
	.000	.000	.000	.000	.000						
Depersonalization	-,395**	-,377**	,539**	,521**	,467**	-,517**	1.000				
	.000	.000	.000	.000	.000	.000					

Factors	Empathy and congruence	Unconditional acceptance	Avoidance mechanisms	Distance and impatience towards the patient	Emotional exhaustion	Professional fulfilment	Depersonalization	Self confidence, dignity and meaning when faced with adversity	Close relationships and personal well-being	Fear of dependence, physical degradation and loss of control	Self criticism regarding time for family, friends and meaningful activities
Self confidence, dignity and meaning when faced with adversity	,576**	,416**	-,321**	-,242**	-,425**	,574**	-,411**	1.000			
	.000	.000	.000	.003	.000	.000	.000				
Close relationships and personal well-being	,390**	,318**	-,237**	-,335**	-,306**	,517**	-,364**	,557**	1.000		
	.000	.000	.004	.000	.000	.000	.000	.000			
Fear of dependence, physical degradation and loss of control	-,238**	NS	,368**	,214**	,539**	NS	,301**	-,416**	NS	1.000	
	.003		.000	.009	.000		.000	.000			
Self criticism regarding time for family, friends and meaningful activities	-,174*	NS	,423**	,208*	,460**	NS	,335**	-,287**	-,181*	,458**	1.000
	.033		.000	.011	.000		.000	.000	.026	.000	

TABLE 34 - CORRELATIONS BETWEEN THE DIFFERENT FACTORS AFTER THE INTERVENTION

These results show the relationships that exist between the different factors. The following sections will show how levels of burnout correlate with levels of the helping relationship and personal well-being, and after the intervention there were stronger correlations between the levels of well-being with both levels of burnout and levels of their perception of the quality of the helping relationship.

<u>The Relationship between Personal Well-Being and Helping Relationship Skills with Levels of Burnout</u>

With the use of the intervention it was hoped that as a result of an improvement in personal well-being and perception of their own competencies of helping relationship skills, there would be a reduction in levels of burnout. These correlations are relevant to the theory presented in the literature review, that personal introspection to improve personal relationships, meaning in life and awareness of personal coping resources can reduce death anxiety, and that this, together with training to improve helping relationship skills can reduce burnout.

The results below support this assumption as there were strong positive relationships between the factors of the helping relationship and burnout and well-being and burnout:

- The negative factors of the helping relationship (avoidance mechanisms and distance and impatience toward patients) and the negative factors of burnout (emotional exhaustion and depersonalization);
- The positive factors of the helping relationship (empathy and congruence and unconditional acceptance and positive regard) and the positive factor of burnout (professional fulfilment);
- The negative factors of personal well-being (fear of dependence and physical degradation and no time for family and meaningful activities) and the negative factors of burnout (emotional exhaustion and depersonalization);
- The positive factors of personal well-being (close personal relationships and meaning in life and self-confidence in face of illness and adversity) and the positive factor of burnout (professional fulfilment).

The results for the positive factors showed a significant and strong correlation between several factors, in particular:

- Professional fulfilment and self-confidence in the face of adversity and illness (r=.58); and close personal relationships and meaning in life (r=.62) (positive factors of death anxiety — that is, personal well-being).
- Professional fulfilment and empathy and congruence (r=.67); and unconditional acceptance (r=.58) (positive factors of the helping relationship).

The results for the negative factors, showed significant moderate correlations between:

- Emotional exhaustion and fear of dependence and physical degradation (r=.35) (negative factor of death anxiety) and no time for family and meaningful activities (r=.52) (negative factor of death anxiety),

- Depersonalization and fear of dependence and physical degradation (r = .35) and no time for family and meaningful activities (r=.49)
- Emotional exhaustion and avoidance mechanisms (r=.56), and distance and impatience (r = .44).
- Depersonalization and avoidance mechanisms (r=.51) and distance and impatience (r = .45).

This confirms there is a relationship between personal well-being/death anxiety and confidence in one's helping relationship skills with burnout.

There were also strong negative relationships between the positive factor of burnout and the negative factors of helping relationship skills and the negative factors of personal well-being and between the negative factors of burnout and the positive qualities of helping relationship and personal wellbeing:

- Professional fulfilment and avoidance mechanisms (r = -.33);
- Professional fulfilment and distance and impatience (r = -.34);
- Emotional exhaustion and empathy and congruence (r = -.3);
- Emotional exhaustion and unconditional acceptance (r = -.33);
- Emotional exhaustion and self confidence, dignity and meaning when faced with adversity and illness (r = -.4);
- Emotional exhaustion and close relationships and personal well-being (r = -.34);
- Depersonalisation and empathy and congruence (r = -.27);
- Depersonalisation and unconditional acceptance (r = -.3);
- Depersonalisation and self confidence, dignity and meaning when faced with adversity and illness (r = -.26);
- Depersonalisation and close relationships and personal well-being (r = -.28).

The following correlations were strengthened after the intervention:

- Emotional exhaustion with self confidence in face of adversity and illness (negative correlation) and fear of dependence and physical degradation (positive correlation);
- Depersonalization with empathy and congruence and unconditional acceptance (negative correlations), and with avoidance mechanisms and distance and impatience (positive correlations);
- Professional fulfilment with distance and impatience (negative correlation).

The pre-intervention correlations were useful to establish that there was a relationship between these factors suggesting they could influence each other. The post-intervention analyses which showed stronger correlations suggest that the intervention was successful in increasing personal well-being and confidence in helping relationship skills, and that this influenced the reduction in burnout.

The Relationship between Personal Well-Being and Perception of Competencies of Helping Relationship Skills

It was also hoped that the intervention would show that as a result of an improvement in personal well-being, there would be an increase in their capacity to engage in a quality helping relationship. These correlations are relevant to the theory presented in the literature review, that personal introspection to improve personal relationships, meaning in life and awareness of personal coping resources can reduce death anxiety, which in turn can improve helping relationship skills.

Results show that there is a positive relationship between the positive factors of personal well-being, the positive factors of the helping relationship and the positive factor of burnout and between the negative factors of personal well-being and the negative factors of the helping relationship, in particular:

- Self confidence, dignity and meaning when faced with adversity and empathy and congruence (r =.47); and unconditional acceptance (r = .51);
- Close personal relationships and empathy and congruence (r = .44); and unconditional acceptance (r=.44);
- No time for family and meaningful activities and avoidance mechanisms (r = .48); and distance and impatience (r = .33);
- Fear of dependence and physical degradation and avoidance mechanisms (r = .38).

The significance of these correlations was maintained after the intervention and there were stronger correlations between personal well-being and the perception of helping relationship skills. Some of these were non-significant before the intervention and became significant after:

- No time for family and meaningful activities and empathy and congruence;
- Fear of dependence and physical degradation and empathy and congruence;
- Self confidence, dignity and meaning when faced with adversity and empathy and congruence;
- Avoidance mechanisms and empathy and congruence;
- Close personal relationships and distance and impatience.

This suggests that existential well-being has an impact on the HCWs' capacity to engage in an effective and meaningful relationship with the patient and family.

Section Summary

These results showing the relationships between the different factors are important to understand how personal well-being, death anxiety, burnout and the quality of helping relationship skills are all interrelated, reinforcing the need for an intervention that simultaneously addresses all these issues.

The results of the pre-intervention correlations were useful to establish that there was a relationship between these factors.

More specifically:

- The positive correlations between “empathy and congruence” versus “professional fulfilment”, “self confidence, dignity and meaning when faced with adversity”, “close relationships and personal well-being” and “avoidance mechanisms” shows that HCWs, who had high skills in empathy, were genuine with the patient and congruent with themselves within the relationship with the patient, scored high on professional fulfilment and personal well-being and low on avoidance mechanisms. This suggests that if HCWs are able to become more empathic, without the need to protect themselves by using avoidance mechanisms, they may become happier at work.
- The positive correlations between “avoidance mechanisms” versus “emotional exhaustion”, “depersonalization”, “fear of dependence, physical degradation and loss of control” and “self criticism regarding time for family, friends and meaningful activities” shows that HCWs who scored high on avoidance mechanisms, also scored high on burnout and factors related to death anxiety. This suggests that someone who defends themselves from getting emotionally involved with the patient may be doing so due to their own personal fears of life and death and this may not avoid burnout.
- The positive correlations between “emotional exhaustion” and “depersonalization” versus “no time for family, friends and meaningful activities” and “fear of dependence, physical degradation and loss of control” shows that HCWs who scored high on burnout (with higher scores for emotional exhaustion + depersonalization), also scored high in factors related to death anxiety. This suggests that the more health care professionals live their lives with meaning and personal satisfaction, the more able they will be able to enter a meaningful relationship with the patient, without the risk of suffering from burnout.
- The positive correlations between “no time for family, friends and meaningful activities” versus “fear of dependence, physical degradation and loss of control” and “emotional exhaustion” shows that HCWs who scored high on “no time for family, friends and meaningful activities”, also scored high on factors related to death anxiety and burnout. This may suggests that the more HCWs invest in their personal relationships – (close ties with family, and a strong network of friends) – the easier it will become to accept depending on others if they become old or ill. It may also suggest that the more investment in personal relationships and meaningful activities – the easier it will be to avoid burnout.
- The negative correlation between “self-confidence, dignity and meaning when faced with adversity and illness” versus “fear of dependence, physical degradation and loss of control” shows that HCWs who scored high in “self-confidence, dignity and meaning when faced with adversity and illness”, scored low in factors related to death anxiety.

The post-intervention analyses which showed stronger correlations suggested that the intervention was successful in increasing personal well-being and confidence in helping relationship skills and in reducing death anxiety, and that this influenced the reduction in burnout.

More specifically:

- HCWs who scored high in self-confidence, dignity and meaning when faced with adversity and illness, also scored high in empathy and congruence, and low in avoidance mechanisms;
- HCWs who scored high in close personal relationships and personal well-being also scored low in avoidance mechanisms;
- HCWs who scored high in fear of dependence, physical degradation and loss of control also scored high in avoidance mechanisms and low in empathy and congruence;
- HCWs who scored high in emotional exhaustion, also scored high in fear of dependence, physical degradation and loss of control and low in self confidence, dignity and meaning when faced with adversity and illness;
- HCWS who scored high in depersonalization also scored high in avoidance mechanisms and distance and impatience and low in empathy and congruence and unconditional acceptance.

This suggests that the training had a positive influence in increasing confidence, dignity and meaning when faced with adversity and illness and in reducing fears of dependence and physical degradation (i.e. reducing death anxiety), and this in turn improved helping relationships skills. This, together with the reduction in burnout, supports the importance for health care workers to have emotional support and training in this area of work.

4.2.7 CONCLUSION FOR QUANTITATIVE RESULTS

In conclusion, the quantitative results showed significant improvements after the intervention in all factors, excluding “self criticism regarding time for family and meaningful activities”. However, when separating HCWs within PCUs and other units, this factor showed a significant improvement in HCWs working in other units. The results also showed stronger correlations after the intervention between personal well-being, perception of helping relationship qualities and burnout. It would seem therefore that there is evidence that there has been a real reduction in burnout and an increase in the participants’ ability to cope with the work surrounding death and dying and that improved personal well-being had a positive effect on perception of helping relationship skills and that both personal well-being and improved perception of helping relationship skills had a positive effect on burnout.

5. QUALITATIVE RESULTS

CHAPTER OUTLINE

The first section describes the participants involved in the qualitative analyses of both the written answers and the face to face interviews.

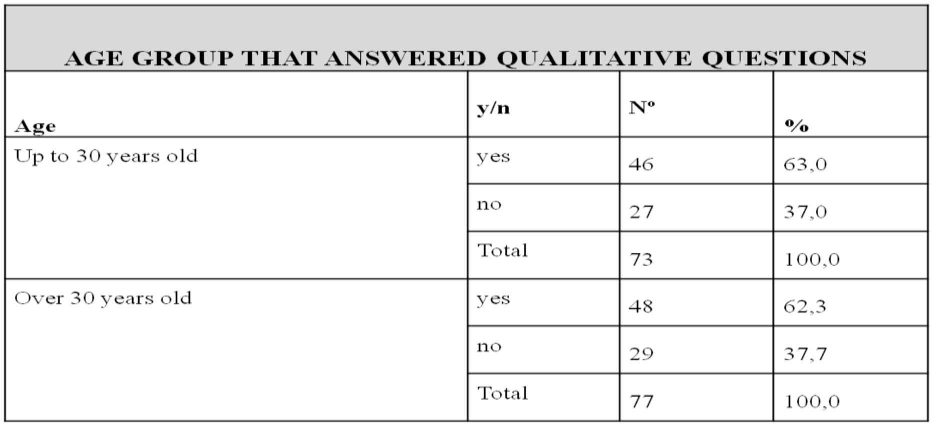
This second section consists of two main parts, pre-intervention analysis and post-intervention analysis, distinguishing between HCWs working in PCUs and in other units. The first part analyses data collected by the researcher during each of the 29 interventions with an average of 7 to 8 participants per group, regarding the particular difficulties felt by the participants at work. As the participants spoke, their comments were written on the blackboard, and subsequently transcribed into the researcher's notebook. Using NVivo, the data were organised into categories as can be seen in fig 37.

The second part analyses post intervention data collected 4 months after the intervention from 94 participants who filled in the open ended questions from each post-intervention questionnaire (see table 36 and 37 below), and 26 participants who underwent individual face to face interviews (table 38 below). It shows the feedback of the participants on the intervention itself, the impact on the quality of their relationship with patients and families, the personal changes, gain in knowledge and finally the needs and negative aspects still present.

The final section includes an examination of the contrasts between the qualitative and quantitative data to show how these answer the hypotheses and to understand how these results can contribute towards theory.

5.1 PARTICIPANTS

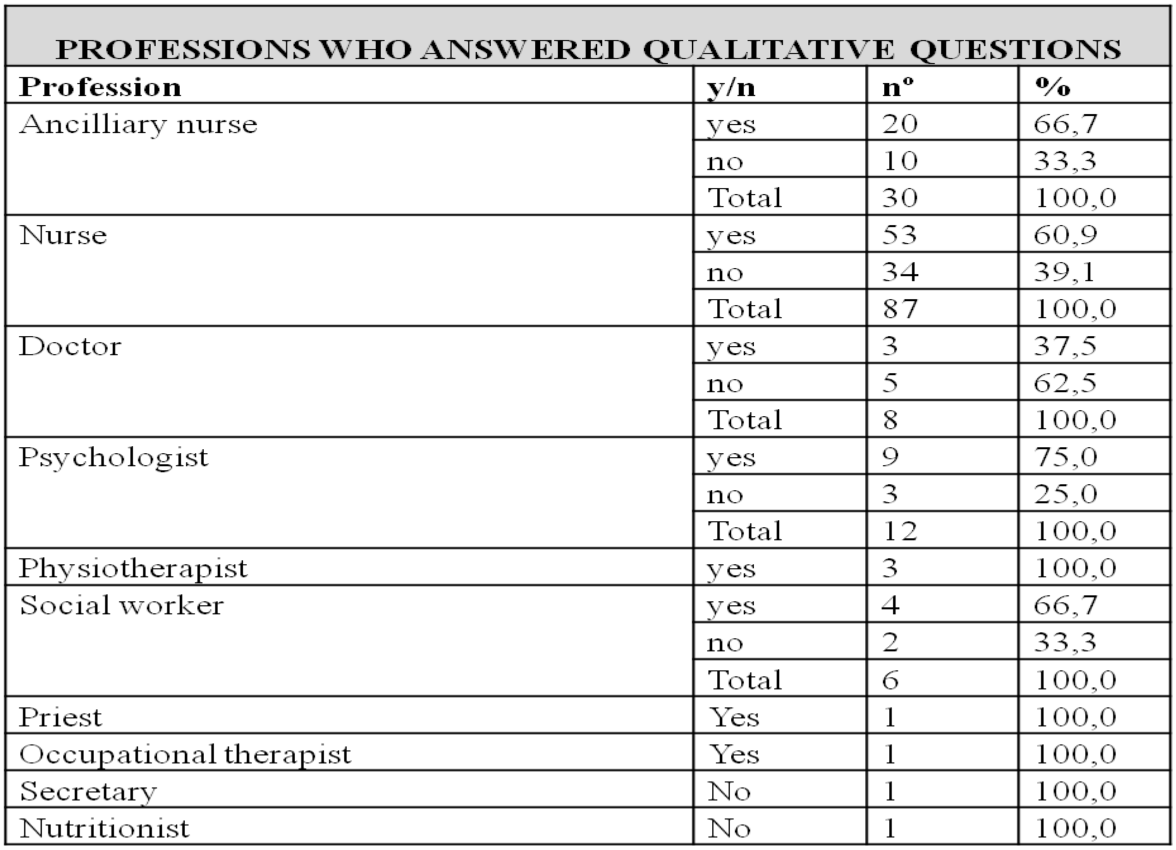
A total of 94 participants answered the qualitative questions, 49 from palliative care units and 45 from other units. In line with the distribution of participants among professions, most of the answers were from nurses and nursing aides. Exact numbers can be seen in the following tables:



AGE GROUP THAT ANSWERED QUALITATIVE QUESTIONS

Age	y/n	Nº	%
Up to 30 years old	yes	46	63,0
	no	27	37,0
	Total	73	100,0
Over 30 years old	yes	48	62,3
	no	29	37,7
	Total	77	100,0

TABLE 35 - PARTICIPANTS - AGE



PROFESSIONS WHO ANSWERED QUALITATIVE QUESTIONS

Profession	y/n	nº	%
Ancilliary nurse	yes	20	66,7
	no	10	33,3
	Total	30	100,0
Nurse	yes	53	60,9
	no	34	39,1
	Total	87	100,0
Doctor	yes	3	37,5
	no	5	62,5
	Total	8	100,0
Psychologist	yes	9	75,0
	no	3	25,0
	Total	12	100,0
Physiotherapist	yes	3	100,0
Social worker	yes	4	66,7
	no	2	33,3
	Total	6	100,0
Priest	Yes	1	100,0
Occupational therapist	Yes	1	100,0
Secretary	No	1	100,0
Nutritionist	No	1	100,0

TABLE 36 - PARTICIPANTS OF QUALITATIVE QUESTIONS

Profession	Nº		Place of work	Nº
nurses	15		in pc	16
aux	6		in other units	10
doctors	3		Total	26
chaplain	1			
admin	1			
Total	26			

TABLE 37 - PARTICIPANTS OF LIVE INTERVIEWS

5.2 QUALITATIVE RESULTS

The original written answers and the interview transcripts were fed into NVivo and coded into themes. An individual report for each main theme was provided by Nvivo, thereby protecting the identity of the participants. Each theme has several quotes from participants, which are referred to as coded anonymised references. These individual reports with all the quotes can be accessed in the appendix of a previous report handed into the Calouste Gulbenkian Foundation for the ability to audit and each section will state which report in the appendix to refer to. After each quote, a reference is written in brackets (e.g.3:1). This corresponds to the quote nº, followed by the page nº of the report in the appendix. The results section only mentions quotes considered most relevant. A model provided by Nvivo is presented in each section, with a summary of the themes and a commentary is provided at the end of each section, summarising the findings and linking them to the literature review. As the categories applied to this analysis relate directly to the type of data collected (i.e. researcher blackboard notes, handwritten comments on questionnaires, or interviews) the quotes that justify the interpretation reflect this.

In total there were 6 main themes and 14 subthemes as shown in the following table:

PRE-INTERVENTION DATA	
Difficulties	Main difficulties related to coping with death and suffering
	Communication with patients and their family
	Feelings of incongruence
	Team and Workplace

POST-INTERVENTION DATA	
Feedback on the intervention	The benefits of sharing in a group
	The methodology of the intervention
Impact on relationships	The relationship with the patient
	The relationship with the family
	The relationship with work colleagues
Impact on self	Personal changes
	Internal congruence
	Well-being in daily life
Gain in Knowledge	
Needs and negative aspects still present at work	Needs
	Negative aspects still present at work

Table 38 - MAIN THEMES AND SUBTHEMES OF QUALITATIVE DATA

These themes will be elaborated in the following sections.

Pre-Intervention Data Collection:

5.2.1 DIFFICULTIES OF HEALTH CARE WORKERS

(Appendix 16 - Difficulties)

The main themes and subthemes associated with difficulties that were mentioned are shown in fig 37. The difficulties that were most frequently mentioned by HCWs can be found in red. They seem to be linked to the health care workers own difficulties in facing illness and suffering. These include avoidance mechanisms so as not to have to face the patient's suffering, not knowing what to say, and therefore ignoring the subject altogether, and difficulty in dealing with the patients' suffering. Health care workers also admitted openly that facing the patient woke up their fears of death, and admitted to their difficulty in not being able to cure them. They often mentioned that by stopping curative treatment and giving palliative care made them feel as if they were giving up. Their strong desire to cure the patient, or difficulty in accepting their incurable disease often led them to have difficulty with boundaries, thereby affecting their personal lives.

Other areas of difficulty were related to communication with the patient and family (shown in yellow), conflicting inner emotions, leading to incongruence (shown in green), and finally, difficulties related to their relationship with work colleagues and the working environment itself (shown in purple).

Although these areas could be delineated there was considerable overlap, as the issues were often related to each other. The various areas will be discussed separately below, and followed by a general comment on this inter-relatedness.

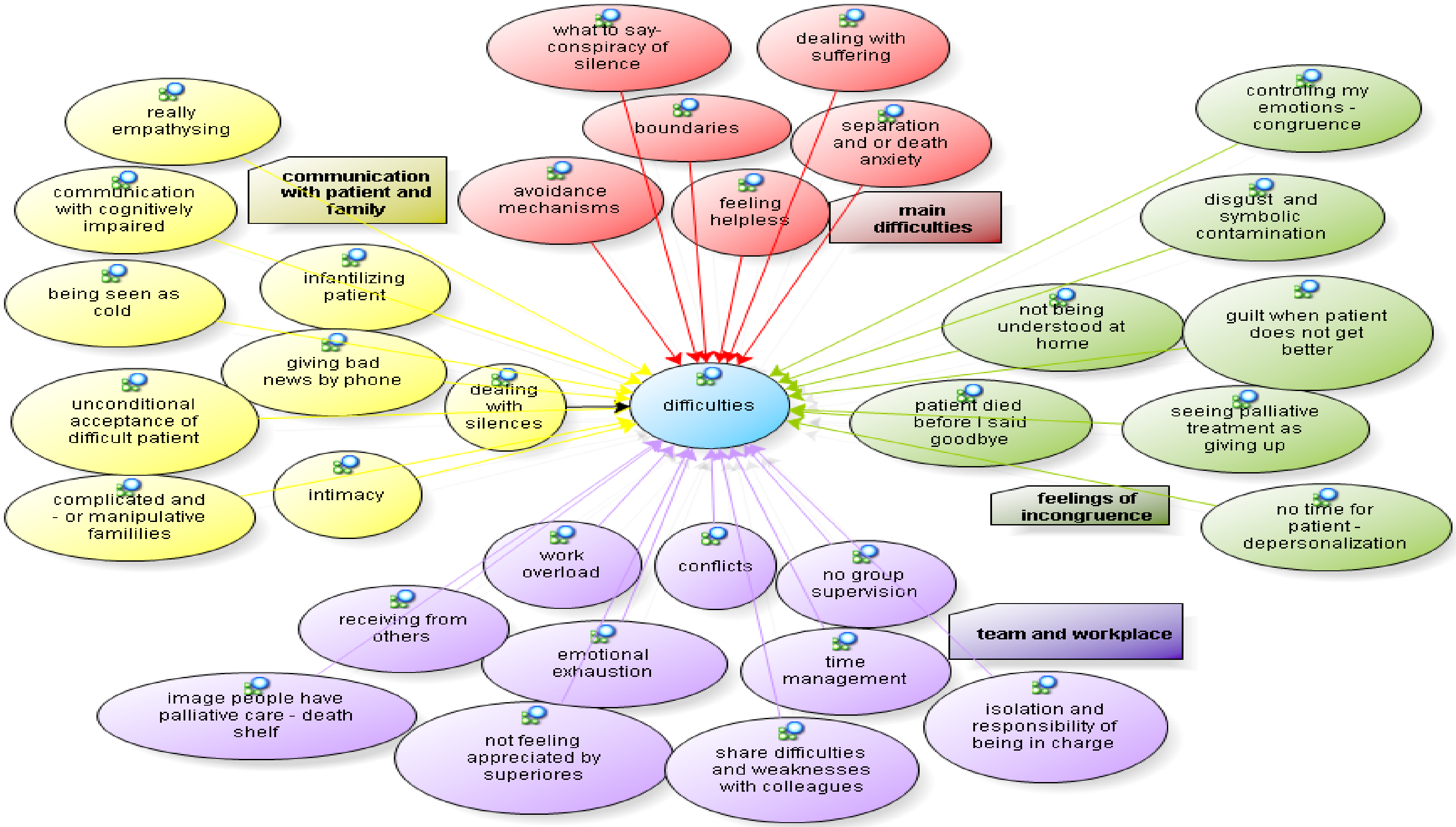


FIGURE 36 - DIFFICULTIES OF HCWS

Following are some illustrations of what health care workers stated in the group. Some of the answers may be short, as they were taken orally from the group during the intervention and written on the blackboard, and sometimes sentences were abbreviated:

Main Difficulties, Related to Coping with Death and Suffering

It was obvious form the participant's responses that there were issues raised associated with the general deterioration and changes within the patients, and the resulting issues for families. They did talk of the difficulties of caring for dying patients as their own fears of death and dying – for themselves or their close family and friends – were awakened. They also talked of the difficulty of coping with the inevitability of death and that the patients could not be cured, and that their own training had emphasised cure and providing palliative care resulted in a feeling of failure and "giving up".

Examples of these issues are:

> *"I find it very difficult to talk about death because I am scared of it" (HCW in other units: 3:23);*
>
> *"Dealing with parents losing their children" (HCW in PCU: 6:9);*
>
> *"I take problems home. I feel it is my duty to alleviate the weight of their suffering" (HCW in PCU: 2:3);*
>
> *"Difficulty to accept our limitations. When must we stop treatment? I feel as if I am giving up on the patient" (HCW in other units: 2:22);*

Avoidance Mechanisms

HCWs talked of finding it difficult to face the fears and suffering of patients, and often resorted to avoidance mechanisms, but they were aware that this might not be helpful in the longer term. They talked of their fear of not being able to cope with all of the patient's fears and anxieties and how this can affect their personal well-being:

> *"I avoid looking them in the eyes when I don't want to talk..." (HCW in other units: 10:1).*
>
> *"I am afraid of getting involved with the patient, so I put on a mask, but I fear that this mask is spreading to my private life" (HCW in other units: 3:1).*
>
> *"It is difficult to accept death and suffering, so I defend myself by avoiding the patient…..but then I suffer anyway, because I feel I haven't helped the patient" (HCW in PCU: 4:1).*

These difficulties are not just related to the dying patient, but also extend to the families' suffering, where HCWs also show discomfort when they are at a loss of words:

> *"…facing the families' reaction when the patient dies. I don't know what to say, so I avoid them." (HCW in PCU: 5:1).*

Boundaries

Participants showed evidence that they coped on occasions by allowing the boundaries between work and home to be blurred. This was related to their own feelings of powerlessness, as they felt that their training had been to cure patients, whereas in the care of the dying they were dealing with therapeutic failure:

> *Suffering with their suffering: what do I do? What I do is not enough..." (HCW in PCU: 6:3).*

Comments were also made that showed that they were experiencing difficulty in accepting limitations and boundaries because the patients were a reminder of their own personal losses or they were projecting their own feelings and family situations onto the patients and families, for whom they were caring:

> *"I suffer a lot with the families, because I have been through the same thing" (HCW in PCU: 4:1)*
> *"Creating bonds with young patients and then losing them"; (HCW in PCU: 16:1);*
>
> *"Caring for family members that are my age" (HCW in PCU: 17:1).*

Dealing with Suffering

HCWs showed that they had difficulty in dealing with suffering - work overload; difficulty in expressing their sadness with others about patients who have died; time to grieve was not always available; they felt they were disrespectful towards the patient when they had carry on as if nothing had happened:

> *"I need an interval between patients to recompose"(HCW in other units: 2:9);*
>
> *"We feel that we have to get over the patient's death quickly" (HCW in PCU: 11:9).*

They also talked of the issues of with their own personal reactions towards the meaning of suffering, especially when children and their parents were involved and the situation could be close to their own family situation:

> *"Feelings of anger and injustice over so much suffering" (HCW in other units: 4:9);*
>
> *"It is better to die than to suffer. What is the meaning of suffering? (HCW in PCU: 25:9).*

> *"Accepting death in young people: talking to a young father or mother who is dying, and talking to their family" (HCW in PCU: 32:9).*

HCWs who worked out of PC units found the transition from curative to palliative care difficult to cope with. Whereas HCW in PC units received patients with the sole purpose of giving them as much quality of life as possible until their death, HCWs in other units live throughout the whole process of treatment with their patients.

> *"Problems with the physical degradation of patients: it is ok if they are still full of hope, but I don't know what to do when they relapse and loose hope. I feel bad, because I know them well, and I really want them to get cured" (HCW in other units: 17:11);*

Nurses and nursing aides also expressed their frustration when doctors would not prescribe adequate pain control medication. Not only did it make them feel helpless, but they also mentioned how difficult it was to cope with. Whilst working, it is not possible to close one's ears, and some found audible expressions of suffering disturbing:

> *"Dealing with physical pain when doctors won't collaborate to reduce their pain. It happens a lot because they think that giving pain medication will accelerate their death" (HCW in other units: 20:11).*
>
> *"Listening to patients moan" (HCW in PCU: 24:12).*

Separation and Death Anxiety

Caring for the dying raised some existential anxieties about life and death and reminded HCWs of what it would be like to never see their own loved ones again. Death and not knowing what happens after death was seen as scary and cold:

> *"Understanding and accepting death…difficulty with separation, even though I believe in life after death, in reincarnation and that we come here with a purpose…" (HCW in PCU: 1:23);*
>
> *"Thinking that there is nothing after death" (HCW in other units: 5:23);*
>
> *"Preparing the corpse – the person is cold" (HCW in PCU: 9:23) (preparing the corpse was also mentioned by HCWs in other units);*
>
> *"Taking the patient to the mortuary – it gives me the creeps" (HCW in other units: 7:23).*

What to Say – Conspiracy of Silence

Even though caring for patients with a terminal condition was their full time job, HCWs still felt unprepared at times, emphasising the need for more training and emotional support. Some comments showed they were afraid that the conversation may harm the patient and this occurred both in and out of PC units. This reinforces the argument that personal development in the area of death anxiety is needed to complement traditional training in end of life care:

> *"How far can I go when talking to the patient – I am scared of doing them harm" (HCW in PCU: 3:26);*
>
> *"Having to hide my feelings in front of the patient" (afraid that showing any sign of worry, that they will be harming the patient) (HCW in other units: 15:26).*

HCWs, mostly in other units, also showed evidence of concern at being taken off guard and not knowing what to do or say. This could often end up in inappropriate remarks that they immediately regretted saying, but it was too late….

> *"Defence attitudes that end the conversation. We still say things like "Never mind, I am worse off than you are today!" (said in a playful way), or "We are all going to die one day. I might even go before you" (HCW in other units: 9:26);*
>
> *"Feeling helpless leads us into this. For example, one patient was being transferred to the ICU and the nurse said – 'See you when you get back' - and the patient answered –'Thank you for everything you have done. I'm going to die' -. It was terrible for them, and they didn't know what to say." (HCW in other units: 16:26);*
>
> *"I know all the theory, but I do it anyway, because I am very aware of what is coming" (HCW in other units: 18:26).*

However, as shown later in this chapter, post intervention comments will show that this fear is appeased when HCWs have worked on their own personal existential fears.

HCWs expressed the difficulty in having a genuine and truthful conversation that would simultaneously allow patients to have hope, albeit without creating false illusions, but were also afraid that the truth could crash their hopes:

> *"Answering difficult questions. How to not take away hope, but not create illusions? (HCW in PCU: 22:26);*
>
> *"How can I talk about death when it is not imminent?" (HCW in other units: 11:26);*
>
> *"What do I say when they start talking about death?" (HCW in other units: 12:26).*

Feeling Helpless

As mentioned above in the section on boundaries, HCWs could not help from feeling bad when they couldn't stop death from occurring. The following comments shows that when death occurs, conditions were not always optimal and this, participants had difficulty with, especially when they were working in palliative care, a place they had chosen to work in especially so that they could make a difference:

> *"Knowing what the person needs to die in peace and not being able to do anything about it" (HCW in PCU: 3:14);*

Other comments show that in spite of the battle of palliative care HCWs in society against the sentence "there is nothing more to do", this feeling persists amongst HCWs, especially in those working in other units:

> *"Waiting for the end – feeling helpless for not being able to do anything" (HCW in other units: 34:14);*

> *"What to do in the end when there is no cure: Feeling helpless and as if I have failed" (HCW in other units: 7:14);*

Feelings of helpless were also shown by HCWs who are taken by surprise by patients, leaving them at a loss for words:

> *"What do I say when the patient says "Don't let me die?" (HCW in other units: 8:14).*

Difficulties Related to Communication with Patients and their Family

Difficulties in communication were analysed taking into consideration the theory of Person Centred Counselling, where the person helping the other needs to fulfil certain conditions. HCWs need to be able to empathize with the other and do so in a manner that the other feels understood, to unconditionally accept the other without judgement and to be congruent and genuine with the other within the helping relationship. It was apparent that these difficulties were felt both in and out of palliative care units.

The Capacity to Empathize and Communicate this to the Patient

Some HCWs found it difficult to really put themselves in the other person's situation and others felt they were able to, but did not know how to convey this to the patient in a manner that they could understand, resulting in feelings of incongruence on behalf of the HCW. This compromises an effective helping relationship, where HCWs need to convey their empathy in a manner that patients will really feel understood:

> *"Really understanding them and their expectations" (HCW in PCU: 1:21).*

> *"Giving bad news….. I really feel their pain, but I don't know what to do or say, so I avoid them, and am then seen as cold" (HCW in PCU: 3:3).*

By listening to the groups talking, the researcher was able to understand aspects that were not always clear to the participants. For example, by infantilizing elderly or frail patients, participants may have been sympathetic, but not empathetic:

> *(Author's note): "I noticed some tendency to treat the elderly as children. The health care workers talked about caressing the elderly person's cheek and being rejected and not understanding this aggression. However, from the way this was described, the way they addressed the person, was as if he were a child" (HCW in other units: 1:17).*

Unconditional Acceptance of Difficult Patient

HCWs shared within the group that unconditional acceptance is not always easy, depending on the patient. They found it much easier to be accepting and non-judgemental towards a patient who is pleasant or emanates vulnerability, than a patient who puts up a front:

> *"When the patient's look is one of pain, we help, but if it is a look of superiority, we take a step back. It is difficult to be tolerant when they look at us with hate. It is also difficult to accept drunks and drug addicts." (HCW in other units: 1:26).*

Relationships with families also proved to be a challenge when the family did not visit, or rarely visited. HCWs found it difficult to care for a patient who is frail and pleasant and remember that perhaps they were not always that way, making it difficult for them to stay neutral, although they knew that theoretically, they should:

> *"Judging family members who never visit" (HCW in PCU: 2:26).*

Another type of difficulty related to unconditional acceptance was manifested with families who were complicated and manipulative.They were described as "arrogant" and "demanding":

> *"When the family is aggressive with the unit" (HCW in PCU: 2:6);*

> *"What to do when the family "suffocates" the patient" (HCW in other units: 3:6).*

Internal Incongruence

Loss of internal congruence occurs when the harmony between what HCWs feel, do and say is lost, and this can be expressed in a variety of ways. Sometimes HCWs feel frustrated and helpless when trying to communicate with a patient who no longer has the capacity to express themselves, or when they choose to remain silent:

> *"Feeling helpless when communicating with someone who can no longer talk" (HCW in PCU: 6:6).*

> *"...what bothers us is the indifferent look: there is no psychological interaction even though we try. The person has given up, and we don't know how to reach them" (HCW in other units: 2:8);*

> *"Communicating when the patient doesn't talk, either because he is too sick, or because he doesn't want to." (HCW in other units: 3:8).*

Feelings of incongruence can also occur when the HCWs are cornered by patients who ask what they consider to be "difficult questions" or when the patients steer the conversation towards issues the HCW does not feel comfortable with:

> *"...difficulty with direct questions such as 'Do I have cancer?'" (HCW in PCU: 3:17).*

> *"...difficulty when talking about emotional or spiritual matters" (HCW in other units: 5:17).*

Sometimes, the HCW can be taken by surprise with unpredictable situations of intimacy, for example when a patient suddenly decides to confide something intimate, or takes the person's hand, or starts to cry and the HCW is not given time to reflect on what to do:

> *"...unpredictable situations of intimacy" (HCW in PCU: 1:17).*

Feelings of Incongruence

Feelings of incongruence do not occur only in relation to communication issues. Sometimes HCWs find it difficult to control their own emotions:

> *"Body language: the truth comes out when I am not feeling congruent" (HCW in other units: 2:7);*

> *"Internal incongruence when trying to hide from the patient what I feel" (HCW in other units: 3:7).*

Working with patients with a terminal condition can be quite gruesome in terms of smells, sounds and sights. HCWs may feel disgusted, or they may feel they are being "contaminated" even if intellectually they know this is not the case:

In relation to smells that some find particularly difficult to handle, several mentioned vomit, smells caused by ear nose and throat carcinomas or melaena and others described how sometimes they were physically unable to handle it*;*

> *"Difficulty with certain smells, to the point of sometimes having to leave the room" (HCW in other units: 4:13).*

In relation to ugly sights, some found it difficult to know what to do. If they pretended all was fine, the patient would know they were lying, but they were also afraid to talk about it and make the patient feel embarrassed:

> *"How not to make a face when the wound is very ugly; Pretending creates awkwardness" (HCW in other units: 2:13);*

The following was an example of "symbolic contamination". Although the HCW knows that a wrapped chocolate is not contaminated by the air of the room, they still have difficulty eating it. However, they also said that once they got to know the person well, and began to feel affection, this feeling disappeared:

> *"I can only accept chocolates from a patient if I know them well and feel affection" (HCW in other units: 3:13);*

A common difficulty amongst these HCWs was the fact that they could not talk about their work at home like people who have other professions can, because families do not want to hear about 'morbid things', and some find it hard to understand why they would want to work in such an atmosphere:

> *"Not being understood at home, so I take refuge in my work colleagues" (HCW in PCU: 1:20).*

Doctors also let down their barriers and spoke about their feelings of incongruence, when unable to cure the disease:

> *"…Giving bad news when there is no cure and talking of death. I tend to run away from the patient because I can't cure them, and I feel that I have let them down. And then I feel guilty for running away" (doctor in other units: 1:16).*

HCWs develop a strong relationship with their patients, especially with long or repeated admissions, and sometimes death comes unexpected, leaving them with a feeling of unfinished business when they did not have the opportunity to say goodbye:

> *"The patient died before I said goodbye. It's stuck in my throat" (HCW in PCU: 1:21).*

In Portugal palliative care is still a relatively new area of medicine and the concept of stopping curative treatment is still difficult for some HCWs who see this as "giving up":

> *"I find it difficult to create diets for terminal patients, because I feel as if I am giving up on them" (HCW in PCU: 1:22);*
>
> *"Dealing with the families and the transition from curative to palliative" (HCW in other units: 3:22);*
>
> *"What to do when the doctor wants to continue curative treatment until the end? Nurses are divided because they also feel lost when they understand there is no cure, but at the same time, to continue to treat the patient with aggressive treatments is violent, because as nurses, we are trained to care for the well-being of the patient, and giving chemotherapy to a dying patient is not giving well-being" (HCW in other units: 6:22).*

Caring for patients with a terminal condition should be done with time to spend with patients. Following are two comments, one from a HCW who mentioned that she chose to work in palliative care because she wanted to be able to provide "a different kind of care", however, as the unit started to accept more and more patients, this became impossible. The other is from a HCW in other units, showing the same kind of problem:

> *"How do I give quality time with no time?" (HCW in PCU: 2:19);*
>
> *"I know that presence can help to alleviate pain, but in our unit, where there is no time, this is utopia. As there is no time to talk to the patient, when I understand that the patient wants to start a conversation, either I leave the room, change the subject or don't answer" (HCW in other units: 3:19).*

Team and Workplace

HCWs also mentioned difficulties related to their working colleagues and the working environment:

Work overload was a common complaint and this also caused exhaustion, feelings of dissatisfaction because they knew they were not providing the care the patient deserved and also personal problems due to overtime. This was manifested particularly by HCWs in PCUs.:

> *"Feelings of anger for not being able to find time to be with the patient" (HCW in PCU: 2:25);*
>
> *"Feeling incongruent when I feel I should stay but am being pulled to leave by another person or patient" (HCW in PCU: 3:25);*
>
> *"Lack of time: if we go home on time to be with the family and have a balanced life, we are overloading the next shift" (HCW in PCU: 3:25).*

Conflict between colleagues also seemed to be a problem:

> *"Colleagues not being direct. Gossip" (HCW in PCU: 1:7);*
>
> *"Many internal difficulties, conflicts and inflexibility on behalf of the chief" (HCW in other units: 2:7).*

In Portugal, as palliative care is a relatively new medical specialty, it is still not well understood by either the public or the HCWs. This can prove to be particularly frustrating for those working in palliative care units, particularly as the hospitals do not provide emotional support for their employees or supervision. Some participants did not feel supported or understood by their superiors:

> *"The image people have of palliative care: the place where you go to die. Some people even think that the patients are tidied away on shelves waiting for death. How do we re-educate them?" (HCW in PCU: 1:17).*
> *"Patients are put behind the curtain when they are dying so as not to upset the other patients. When I talk to the doctors about this, they say "You're still young". This upsets me" (HCW in other units: 2:21).*

Likewise, some superiors also shared their difficulty of being in charge:

"Dealing with the expectations of workers who ask for help" (HCW in other units: 1:18);

"The isolation of being chief" (HCW in PCU: 2:18).

Although participants mentioned lack of emotional support as a difficulty, some also shared their difficulty in talking about their weaknesses with colleagues:

"Showing our vulnerabilities" (HCW in other units: 2:24);

"Feeling ashamed: he who cries is weak" (HCW in PCU: 3:24).

Comment

These difficulties reflect those mentioned in the literature review. Feeling unable to control the conversation, coping with collusion and knowing how to answer difficult questions such as "How long do I have to live" was discussed by Friedrichsen and Milberg (2006) and the different types of defensive behaviours used by HCWs to protect themselves was discussed by Back et al. (2005). These results also seem to confirm the suggestion in the literature review that these behaviours are not helpful and may contribute towards feelings of guilt resulting in burnout (see section 2.2.2 on giving bad news and avoidance behaviours). This seems to be the case with HCWs working in PCUs and in other units.

These behaviours and feelings of guilt stem from the difficulty of accepting the limitations of medicine and several authors (Williams, et al., 2005; Currow & Hegarty, 2006; Whippen & Canellos, 1991) have discussed this and how it can lead to burnout. The findings of this study reflect these same issues, when for example the participants mention feelings of guilt when unable to cure the disease. However, comments related to emotional difficulties in accepting the inability to cure was mentioned only by HCWs in other units.

Difficulty in coping with boundaries was mentioned by HCWs mostly in PCUs, for example when caring for children, people the same age as them, or people who remind them of loved ones and this was also mentioned in other studies (Payne, 1998; Williams, et al., 2005). The literature review also focused on the work of Marie de Hennezel, who suggests that the solution to this is not to abstain from creating close relationships, but that HCWs need to learn how to create the right distance, meaning that the HCW is sufficiently self aware and congruent to be able to accept the psychological and physical intimacy of exchanges and simultaneously recognize their own fears, failures and vulnerabilities (see section 2.2.1 on death anxiety and unresolved grief). However, for this to occur, HCWs need space of their own. These findings, as well as others (Fawzy, et al., 1991; Florio, et al., 1998; Vachon, 2000; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008; Kearney, et al., 2009), have shown that HCWs need space and time to grieve over their losses too, so that they may replenish and continue to be able to give to their patients (see section 2.2.1 on bereavement and compassion fatigue).

Death anxiety was discussed in the literature review, in the form of anticipating oneself dead, fear of the process of dying and fear about the death of significant others by Neimeyer, (1994, 2003) and in the form of fear of physical change and dependency by Berthon, Pronost, & Tap (1996); Payne, (1998); Lawton, (2000); Abdel-Khalek (2002); Mercadier (2002) and Pereira, (2011), and these fears were also mentioned by the participants in this study, both in and out of PCUs. (See section 2.2.1 on death anxiety) and Jones (1998) also stressed the need for HCWs to have a space where they can reflect on their own personal issues.

Difficulties that HCWs sometimes present with the unconditional acceptance of difficult patients and families is also an issue that has been researched elsewhere (Florio, et al., 1998; Vachon, 2000; Keidel, 2002; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008; Pereira, 2011) and Youngson (2011) has argued that a change in the HCW's personal attitude can have an immediate effect on 'difficult patients', especially in relation to their ability to empathise. This reinforces the need for HCWs to be supported in their difficulties.

Finally problems at the workplace, related mostly to excessive workload has been mentioned repeatedly in the literature (Fawzy, et al., 1991; Whippen D.A., Canellos, G.P., 1991; Ramirez, et al., 1995; Vachon, 2000; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008; Kearney, et al., 2009; Pereira, 2011).

The participants of this study, especially those in PCUs, elaborated further on the consequences of work overload which seemed to have caused many other problems, such as feelings of incongruence for not being able to give sufficient quality time to the patient, conflicts within the team and no time for team meetings and also, personal problems at home due to excess working hours. In Portugal, the ratio of the number of patients per HCW is much higher than what should occur in palliative care (1 HCW for 10 patients rather than 1 for every 3 patients). Particular to this study also seemed to be the fact that HCWs verbalised their feelings of loneliness. This was mentioned by both head nurses and doctors, who mentioned the isolation they felt being in charge and often being misunderstood by their employees, and by nurses, who felt misperceived by the patient's family as being "cold" when in reality they felt at a loss of what to say and do.

Post –Intervention Data (Written Answers and Interviews)

A summary of the main themes can be found in table 38 at the beginning of this section. As this section is very long, the comment summarizing and reflecting on findings will be performed at more frequent intervals.

Content analysis of the various written questions and transcript of the interviews revealed several areas of interest:

5.2.2 FEEDBACK ON THE INTERVENTION

When asked about what aspects of the intervention the participants most appreciated and found useful, they mentioned the liberty of being able to share within the group, which was made possible by the structure and non-judgemental atmosphere of the intervention. Participants were also asked to comment on the negative aspects of the interventions. These were mainly issues of broken confidentiality between members of the group.

__The Benefits of Sharing in a Group__

(See Appendix 17 which contains comments on relationships between different aspects of the intervention)

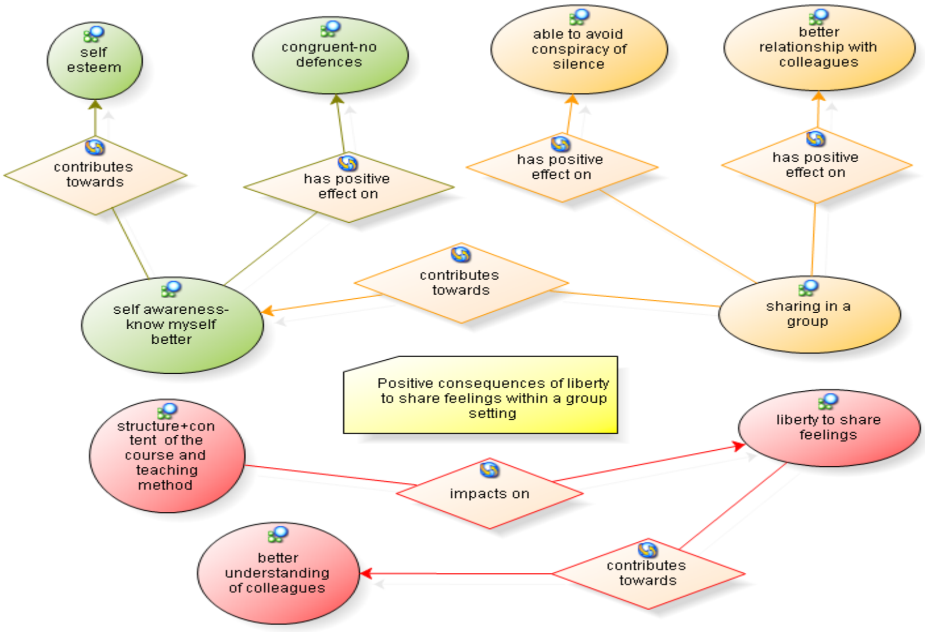


FIGURE 37 - THE BENEFITS OF SHARING WITHIN A GROUP

It seems that sharing within a group and increasing self-awareness was associated with an increase in well-being, both for themselves on a personal level, and in their relationship with patients. As their internal congruence increased, HCWs became more at ease to relate to patients with more authenticity and to their colleagues with more affection:

> *"My self-knowledge really improved. I learned and became aware of aspects of myself that I didn't know and I think I became more confident, improving my internal congruence, daily life and feelings of well-being" (Physiotherapist in PCU: 1:4);*

> *"The main help that the training brought me was the fact that it gave me the possibility to think about myself, and thereby be able to establish a more genuine relationship with my patients" (Nurse in PCU: 1:1).*
>
> *"...more affectionate, because I was considered to be a little cold, and I managed to show affection for my work colleagues...." (Nurse in other units: 1:8);*

Sharing in a group also allowed HCWs to share their difficulties with each other and jointly draw conclusions that things can be done differently, as in the following example where the HCWs reluctance to to allow patients to talk freely could contribute towards the conspiracy of silence:

> *"…I remembered that I had done the course not too long ago and I remembered everything that we all spoke about regarding death, and I remembered the needs of the patient – if he expresses the need to talk, it is because he really needs to talk and we shouldn't run away, and the examples we gave in the course helped me to talk with that mother…" (Nurse in other units: 1:8).*

Creating an atmosphere where liberty to express feelings is encouraged does not happen by chance. The structure, content of the course and teaching method had an impact on the liberty HCWs felt to share feelings, and this in turn contributed towards a better understanding of their colleagues:

> *"What I really valued was the liberty to express my feelings and the structure of the course really helped with this (Psychologist in other units: 1:2);*
>
> *"For me, what I most valued was the liberty to express my feelings, which in a way allowed the people in the group to know each other better and therefore understand each other better (Nurse in PCU: 1:2).*

Hearing the experiences of different professions also proved to be helpful in gaining more insight into the patients' needs:

> *"The sharing of experiences of different people, of different professional groups helps to understand the problems that can occur at the end of life." (Nurse in other units: 5:1);*

Comment

Being able to share in a group, where there is a non judgmental atmosphere and where confidence and trust between the participants is present, had several benefits such as getting to know themselves better and becoming more congruent. It allowed the people to think about themselves in a truthful way, because they did not need to worry what others were thinking. The members of the team were able to see the person within the professional and this brought the team closer; there was more understanding, communication, collaboration and consequently more team work and less defensiveness and conflicts. On the other hand, having participated in a workshop where they felt the benefits of being more open with each other, of being accepted, with all their qualities and defaults, served as a motivation to carry on outside the workshop. It also enabled them to understand that this could also be beneficial for the patient, and as a consequence, they started being more genuine with the patient and family, avoiding conspiracies of silence and self defence mechanisms. Naturally, all of this also had an impact on their own feelings of self esteem. This seemed to be the case for HCWs both in and out of PCUs.

<u>The Methodology of the Intervention</u>

(See Appendix 18 which contains participant comments on the methodology of the intervention)

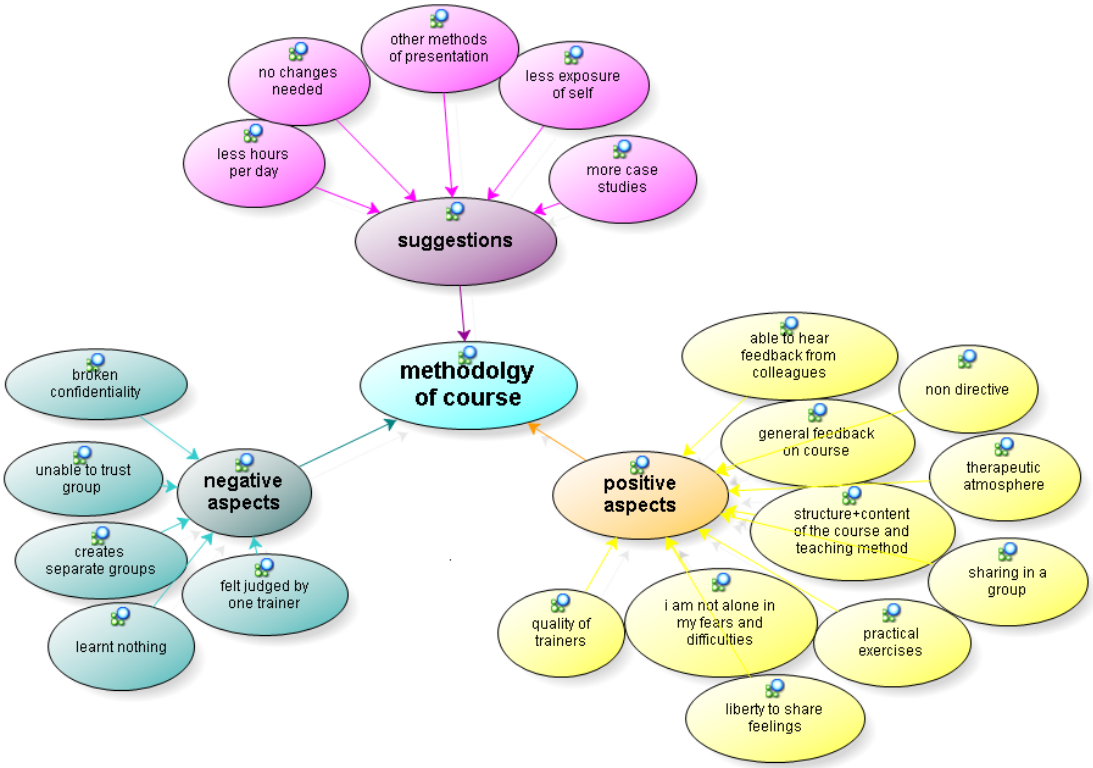


FIGURE 38 - METHODOLOGY OF INTERVENTION FIGURE

Participants were encouraged to talk about both positive and negative aspects of the interventions and to give their suggestions on how to improve the intervention in the future:

Positive Aspects

In an intervention which aims to create a substantial change in HCWs in a relatively short period of time, it is important that the facilitator create the right atmosphere from the start which will allow the participants to make optimal use of the available time. It was apparent from feedback, that the liberty to share feelings within a group, and witness other people's experience was considered of value. The following quotes show how this can be achieved, by promoting respect and unconditional acceptance amongst the participants, and by accepting their rhythm. Also considered of importance was a methodology of inductive learning. The facilitator would first allow the participants to reach conclusions themselves, and only subsequently add complementary information:

> *"What I found most important during the course was the opportunity for each to express themselves without being interrupted, which is something that is more and more difficult nowadays …to be able to put my thoughts and feelings in order, calmly, without being run over; an awakening of consciousness; having to think about things that I had never thought about before, and to bring together loose ideas." (Nurse other units: 25:11);*
>
> *"I particularly liked the style of learning, in the sense that it was more inductive than deductive. We were always lead to first reflect on and experience situations and only after that, to learn theoretical models and theories. I thought the structure was well done, which is not easy in this type of learning. The liberty to express feelings was an element that increased the motivation to be in the course, as well as the opportunity to learn about oneself" (Nurse in other units 2:8);*
>
> *"I valued the way we were given the freedom to express all our feelings, without feeling ashamed or guilty. Being "at ease" was very important" (Nursing aide in PCU: 12:9).*

Another important aspect was the structure of the course which dedicated the first part to the self development of the HCW. This was deemed necessary to help the HCW feel comfortable with their own existential issues, so they could then understand the patients' issues and address them confortably. It is also important that HCWs experience what it is like to be accepted unconditionally, because this may help them provide the same for others:

> *"What I most valued in the training was its informal character, which gave the space to each of us to express ourselves without being afraid of being evaluated for our opinion. This gave us the space to express what we felt and not what we thought we should feel. I found it interesting that the course started with work on ourselves, and only after that approached the patient. Before being health care workers, we are people and only when we can accept ourselves as people, understand our limitations, recognize our strengths, and to know how to look for what our needs are, can we create the space to receive the other, and accept him as he is." (Nurse in PCU: 2:6).*

Sharing in a group was appreciated and found to facilitate growth in many ways, such as being able to hear feed- back from colleagues, which allowed them to see themselves from a different perspective, recognize their own fears and difficulties, and understand that they have many issues in common:

> *"The (therapeutic) atmosphere present helped me to discover how to listen to myself" (1 head nurse in other units:7);*

> *"I have a better idea of what I transmit to others, in terms of what they think of me" (Psychologist in other units: 1:20);*
>
> *"Knowing that others also feel the same difficulties, frustrations and fatigue due to work overload and often not being able to give efficient answers to the needs of patients and families" (Nurse in PCU: 1:2).*

The quality of the facilitators, their non directive approach and the use of practical exercises was also appreciated:

> *"What I most valued in the training was the way it was organized, and the competency of the trainers, the fact that they adapted to each group and situation" (Nurse in PCU: 1:5);*
>
> *"I think that the fact that we came to our own answers was a bonus. Learning about ourselves and above all, self confidence and self knowledge." (Nurse in PCU: 1:12);*
>
> *"...because sometimes, the fact that we have someone that makes us feel if we were to die in a year, what would you want to do, and to verbalize this to the others…. I think we have all thought about it, but to say it out loud to others is a strong point…." (Nurse in PCU: 1:36);*

Negative Aspects

One of the groups was particularly difficult because there were many internal conflicts within the members of the group and the facilitators were not able to create an atmosphere of confidence. Unfortunately, this was commented upon after the course by some members of the group which created more problems, as at the beginning of the intervention, the need for confidentiality was stressed and this contract was breached. In order to reduce some of the harm done, the researcher came back to the unit and spoke to the group as a whole and individually to members of the group that were more affected. The group was encouraged to be honest in their feedback. The issue of trust and broken confidentiality was mentioned and this issue of trust also reflected on the facilitators. Although it was made clear at the beginning of the intervention that participants should only share what they felt comfortable to, and that participation in exercises was not compulsory, the fact that one participant felt she "had to" expose a lot about her private life, shows that this is an aspect that needs to be addressed:

> "Honestly, I didn't really like the training. I had to expose a lot about my private life with work colleagues that I didn't trust." (Nurse in PCU: 1:2);
>
> "This course did not live up to my expectations, because in my group, the confidentiality was broken" (Nursing aide in PCU: 1:1);
>
> "The trainer of the second part arrived with preconceived ideas of the group" (Nursing aide in PCU: 1:1).

Other negative comments, unrelated to this particular group were related to the fact that the course was not given to the whole team at the same time, but to a few members at a time. Participants felt that the intervention contributed towards creating separate groups within the team, who tended to keep more to themselves:

> *"It created groups within the team which is not very positive, because getting along well is good, but there was a rupture with the others…" (Nurse in PCU: 1:34).*

Suggestions for Improvement

(See appendix 25 which contains suggestions regarding the course)

Participants were asked to make suggestions on how to improve the intervention. The majority of participants did not think the course required any changes. One or two people mentioned that the use of power point would help and more case studies would be useful. There were however two issues that were mentioned, the number of hours per day and the amount of self exposure:

> *"I think the training should be longer over time and less compact. The course should be given in more days, with fewer hours per day, because of the emotional exhaustion that it caused in most of us." (Nurse in PCU: 12:3);*

> *"For me, it was a little unpleasant to think that I would be revealing too much in front of my colleagues during some of the exercises." (Nurse in PCU: 1:1).*

The course is quite emotionally intensive due to the sharing that takes place, and in some interventions people were often quite tired at the end of the day. However, spending the whole day together does contribute towards creating an atmosphere of confidence and sharing. Of the 29 courses given, one was given over 12 days instead of 6, and the author felt a difference in the atmosphere created within the group, with less involvement. On the whole however, 6 hours per day with coffee and lunch breaks did not seem to be a problem.

In relation to the amount of self exposure, in the majority of cases, this was not a problem, as an atmosphere of confidence was created right from the beginning, but there were some groups where the people did not share much, and this did affect the group dynamic.

However, these opinions were not shared by everyone:

> *"I really liked this course and the only alteration I would consider pertinent is in relation to the length. It would benefit from being longer and the greatest benefit would be more sharing of experiences" (Nurse in PCU: 2:2);*

> *"Increase the length of the intervention. Six days was little time to teach and assimilate issues of this dimension and depth - they could have been developed further" (Nurse in other units: 10:3).*

Comment

What was most appreciated in the course by the HCWs, regardless of where they worked, was the liberty to express their feelings, and all that this entailed, like getting to know themselves and their colleagues better and realizing that they are not alone in their difficulties. The participants seemed to appreciate the fact that the first part of the course was just self development regarding issues of life and death. It enabled them to experience within themselves, the kind of fears that patients go through, albeit with a lower level of anxiety, as the fears of growing old are not as strong as the prospect of knowing that you are going to die. One participant mentioned that the course was more inductive than deductive, meaning that the self development allowed them to experience and come to conclusions themselves. Consequently, the theoretical issues raised in the 2nd part of the intervention were seen from a different perspective.

Of the 29 groups trained, one course in a PCU did not go well. Unfortunately there was already a lot of mistrust within the group before the intervention, and the facilitator was unable to create a therapeutic atmosphere. Consequently there was not much sharing. This made the whole course less effective, because sharing experiences with one another is one of the main learning instruments of the course. Confidentiality was also not maintained within this group. After the course, the author did speak to the group as a whole, and to some members individually to minimize the negative effects, but this was not enough to repair the damage. This issue will be further developed in the discussion.

The positive and negative experiences that occurred during these interventions reflect clearly the issues approached in the literature review regarding the need for an environment of acceptance and confidentiality. This helps barriers come down and creates trust between HCWs. Feedback from groups where this was successfully achieved and from the groups where it failed clearly showed the benefits and consequences when this does and does not occur (Rogers, 1973; Kasket, 2006).

In the suggestions, there was some controversy over the amount of hours per day. The course could be quite emotionally intensive, often leaving the participants quite tired at the end of the day. On the whole, only a minority saw this as a problem, however this course should really be done with time off work, so participants can dedicate themselves entirely to introspection and have the necessary rest. Those who managed to do this mentioned the positive effect of having taken “time out”. Unfortunately, this was not possible for everyone, and some came to the course direct from night duty and at the end of the day, they felt exhausted.

Self exposure was also brought up on some occasions. Participants were advised from the beginning about confidentiality, and were explained the benefits of being able to share in a non judgemental atmosphere. However, they were put at ease to only share what they felt comfortable with. Culture also played a role, as some participants said that they were not used to this in their country.

5.2.3 IMPACT ON RELATIONSHIPS

The Relationship with the Patient

(See Appendix 19 which contains comments regarding the relationship with patient)

Upon being asked what impact the intervention had on their relationship with the patient, participants mentioned three main areas: improvements in their capacity to be non-judgemental, to give spiritual support and improvements in their communication skills.

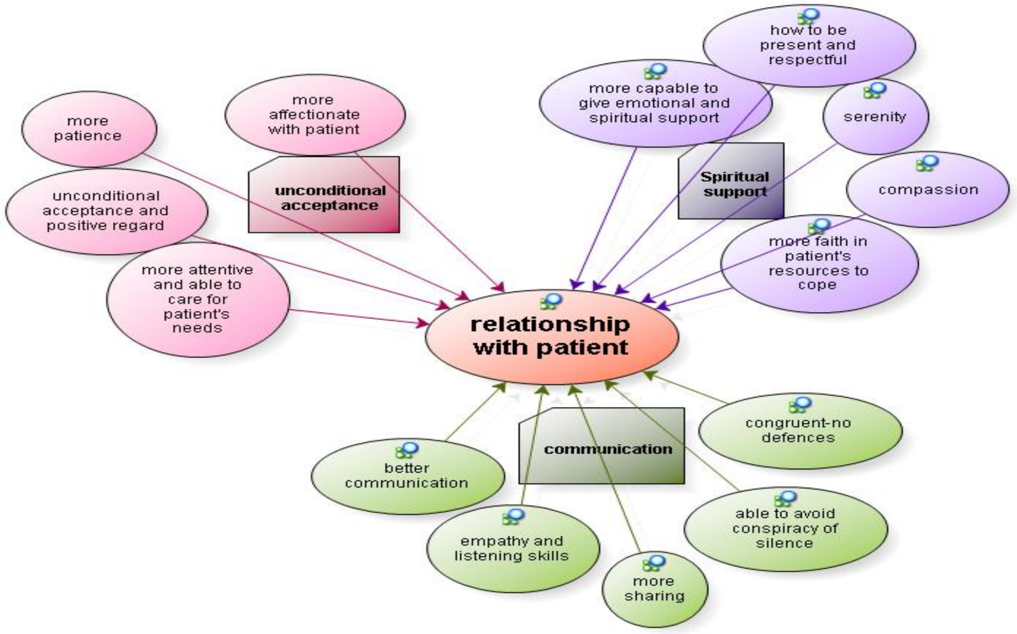


FIGURE 39 - THE RELATIONSHIP WITH THE PATIENT

Death Anxiety and Burnout

(See Appendix 17 which contains comments regarding death anxiety/burnout and the relationship with the patient)

As planned for in the structure of the intervention, HCWs did feel that a reduction in death anxiety and an increase in inner peace had a positive effect on the relationship with the patient, and this may consequently reduce the risk of burnout:

> *"…if we accept death better, and that the patient is here to die, but with more quality of life and less suffering…maybe we will be capable of caring for them differently…not that before we cared for them badly, …we gave the best technically…but perhaps in terms of relationships, we can help the patient in a different way" (Nurse in PCU: 1:7);*

> *"I feel more free and at peace….This allows me to be better with the patient" (Nursing aide in other units: 1:5).*

Unconditional Acceptance and Positive Regard

Allowing the HCWs to work on their own issues first, and be part of a group showing empathy, authenticity and unconditional acceptance towards each other seemed to be effective in creating a better understanding of what the patients are going through and in providing the same caring atmosphere. The capacity of HCWs to be non-judgemental and show unconditional acceptance and positive regard towards patients was shown in a variety of ways, such as attentiveness, affection, patience and a better understanding of their needs:

> *"I learnt to listen, respect, not judge and accept" (Psychologist in other units: 2:5);*
>
> *"It gave me more confidence and motivation in my relationship with the patient. More confidence, because I began to understand the experiences they go through with their illness and losses. More motivated, because I understood how much we can do with simple gestures, with love and with 5 minutes of attention." (Nurse in other units: 2:19);*
>
> *"I learned how to listen to them, to understand something about their pain and to be more patient" (Nurse in other units: 1:26).*

Spiritual Support

Giving spiritual support was not seen as just talking about religious matters, but was related to a whole way of being. Kearney et al (2009) refers to this as 'exquisite empathy'. This can be manifested through an awareness to be present and respectful:

> *"I try to BE more with the patient and not just provide care" (Nurse in PCU: 1:24);*
>
> *"I give more value to the patient. I don't clean so much, so that I can listen more. I don't speak from far away, I go near. I am not afraid of touching the patient during bath time…" (Nursing aide in other units: 1:27).*

Other forms of spiritual support became evident through a gain in knowledge, which enabled them to give emotional and spiritual support with more confidence and also through their own inner serenity which reflected on their capacity to be compassionate:

> *"I felt more capable of helping them cope with all the psychological and spiritual changes that this phase in life implies" (Nurse in PCU: 2:21).*
>
> *"A calmness, serenity, for example, now, we have a young girl who is dying and she was very agitated and all I needed to do was to get a book, start reading, and her breathing changed….." (Nurse in other units: 1:34);*

> *"With the patient, what changed was my capacity to listen and accept the silences...." (Nurse in PCU: 6:35);*

Equally important, was the ability HCWs gained to trust in the patient's resources to cope, and this improved their own serenity to cope with suffering. If carers do not have this faith, there may be atendency to overprotect and according to the theory of the Person Centred Approach in counselling this may not be beneficial in helping the patient grow (Rogers, 1951).

> *"The patient has more resources than I thought. The patient can go through many emotional stages and we must respect this. I am continuously trying to understand him" (Nursing aide in PCU: 1:21);*
>
> *"…Maybe I am not so impulsive in trying to protect the patient and family from suffering, without first listening to them" (Secretary in other units: 1:29).*

Communication

Regarding improvements in their communication skills, most references were made in relation to their empathy and listening skills, followed by their ability to feel more congruent:

> *"I understand how much they are suffering with what they are going to lose. I am more empathic…." (Nursing aide in other units: 3:8);*
>
> *"After the training, my relationship with the patient and family became more genuine" (Social worker in other units: 1:28);*
>
> *"Before, I was afraid to approach the family with certain subjects, because I always thought they would blame us when things didn't go well…." (Doctor in other units: 1:31).*

It seems that the intervention also helped them avoid situations of conspiracy of silence, including HCWs in PCUs, where this should not be happening:

> *"I found ways to deal with questions asked by the patient and family related to the progression of the disease, or to death" (Nurse in PCU: 1:6);*
>
> *"The relationship with the patient improved, because the course helped me to accept that suffering is part of life, and this allowed me to stop running away or avoid talking about these things with the patient" (Nurse in other units: 4:11).*

HCWs also found that they were more at ease to share more with patients and communicate with more confidence. It also seemed that their priorities changed, and time was set aside to spend with them:

> *"Professionally, I think I am better in terms of humanity and relationships because I have changed my time management at work and started to give more value to moments of sharing and listening to the patient." (Nurse in PCU: 1:27);*

> *"The training allowed me to think about how to handle myself with the patient, to think about what to say in certain situations….." (Nurse in other units: 1:12);*
>
> *"I learnt strategies to improve the moments of communication with them, and thereby obtaining information that can help them at this time of their life…." (Nurse in other units: 5:13).*

Comment

As mentioned before, the first part of the course enabled the health care workers to identify and reflect on their fears of life and death, and to realize that these fears are similar to those of patients with a terminal condition, but at a lower level. As a consequence their level of empathy towards the patient increased and their level of death anxiety reduced. Fear is one of the main impediments for a meaningful relationship with the patient as it creates a feeling of uneasiness in the health care worker, who may then become centred on his own feelings rather than on the patient, or do all in his power to reduce these feelings of uneasiness. The consequences are various, from continuing curative treatments that no longer make sense, to over pampering the patient with attentions he does not need. They are all actions that involve doing, rather than being, because doing gives the false illusion of not being "helpless" in the face of suffering and death. Naturally, "doing" is an important part of palliative care, especially in the medical and nursing part, as it relieves pain and provides physical comfort, but it is not as useful in the psychological and spiritual arena. The patient needs to connect with others in order to talk about whatever is on his mind, and this cannot be achieved when the carer is preoccupied with how he can be "useful". The patient needs to feel that the carer has the time and emotional capacity to cope with what he has to say, without falling into the conspiracy of silence and avoiding difficult issues. Deep down, this is also what the HCWs want and the only things holding them back are their numerous fears, such as what to say without causing more grief, losing control of their emotions, or failing in their attempt to help. During the intervention, these issues were discussed, and the HCWs realized that listening and being present is more important than having all the answers and that in fact, the patients do not expect them to have all the answers. They understood that they can be vulnerable and competent at the same time, that it is ok to show emotions, so long as the helping relationship is not inversed and that this will not harm the patient. They also realized that listening, being present and "doing nothing" actually does a lot for the patient. They left the intervention with the "permission" to change their attitude, and this was not really so difficult, because it felt like the right thing to do. The second part of the intervention gave them the tools they needed to provide adequate care, and the first part gave them the emotional capacity to use these tools. Considering the differences between HCWs in PCUs and in other units, the results seem similar. Although it seems that issues related to communication, such as listening skills and unconditional acceptance had a greater impact on HCWs out of palliative care, this was only due to the choice of quotes.

The Relationship with the Family

(See Appendix 20 which contains comments on the relationship with the family)

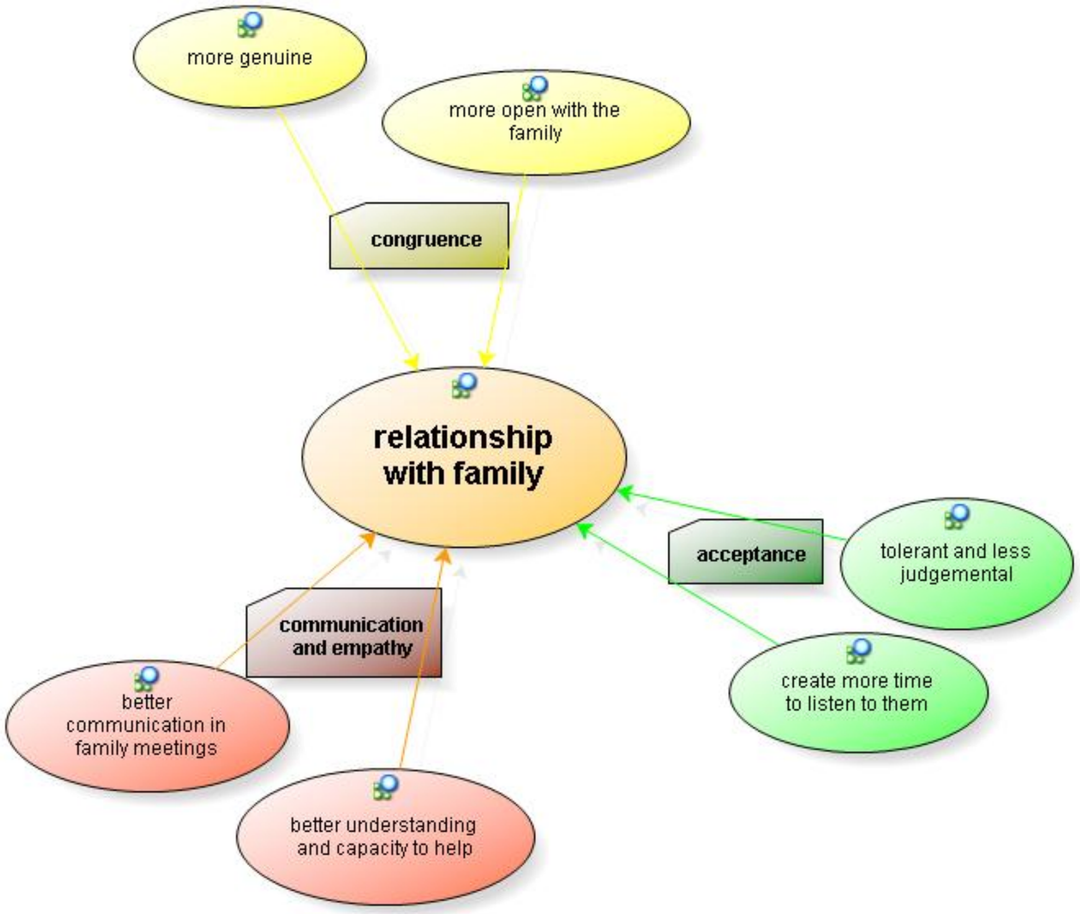


FIGURE 40 - THE RELATIONSHIP WITH THE FAMILY

HCWs also commented that similar effects were obtained with the family.

Congruence

Discussing their experiences with the group helped them understand the value of being genuine and authentic with the family and they were able to reduce their:

> *"Authenticity and honesty that we talked about in the course are essential to be able to help the patient and family get through this period of their lives." (Nurse in PCU: 1:7);*

> *"I feel that this is where I changed my behaviour most. I lost my fears and incapacity to deal with them. And that is when I started to feel much better" (Nurse in other units: 4:7).*

Acceptance

One of the difficulties mentioned in the section on difficulties was accepting aggressive or manipulative families. It would seem that the intervention created a change in this area and HCWs became more tolerant and less judgemental:

> *"It made me rethink about the blame I put on certain families and the difficulty I have in forgiving them. Now I look at the good things they have and try to forgive" (Nurse in other units: 1:8);*
>
> *"I have more respect for the families' feelings. Before the training, I wanted to impose my way of thinking, and today I understand that it is all a question of time and maturing" (Nurse in other units: 6:8);*
>
> *"I am more tolerant when the family talks to us aggressively, as a result of their anger" (Nurse in PCU: 7:9).*

Communication and Empathy

HCWs found that their communication skills and capacity to empathize had improved, and this often helped the family as a whole:

> *"I am more receptive to them sharing their feelings with me. It allows me to help them prepare themselves for their loss and to resolve unfinished business" (Nurse in PCU: 15:4);*
>
> *"Even though I think that in general I have a good relationship with the patient and family, I am more aware and sensitive to details that before, would just pass me by" (Physiotherapist in PCU: 17:1);*
>
> *"I am more attentive to their non verbal communication" (Nurse in PCU: 1:5).*

Comment

Families can be a challenge for the health care professionals for various reasons. Their pain can come too close to home, reminding them of their own family members or increasing their feelings of helplessness to change the course of events, resulting in a tendency to avoid the family. Another reason is that HCWs' may be protective of the patient's well-being which may cause some friction with families. In their desire to help, family members may "suffocate" the patient, or in their refusal to accept pending death they may put a lot of pressure on the patient to "fight", even when it is obvious that the battle is not going to be won. The nurse will understand all this and be protective. Finally, family conflicts or absent families are not easy for HCWs to understand or accept and they may feel angry and judgmental. Sometimes the family's pain is expressed as aggressiveness towards the HCWs, which may be difficult to cope with.

All these issues are discussed during the intervention, and it helps them to understand the families better and to judge them less. They also realize that by helping the family, they are also helping the patient, because one cannot be separated from the other.

In this section, contrary to the previous, it is possible to see that results are similar in HCWs from both in and out of PCUs, including matters related to empathy and unconditional acceptance.

The Relationship with Work Colleagues

(See Appendix 21 – which contains comments on the relationship with colleagues and Appendix 17 for comments relating to how group cohesion can affect the relationship with the patient and work efficiency)

It seems that the intervention improved relationships with work colleagues and this had an effect on the harmony felt within the team, on the way they communicated with each other and on their capacity to work as a team. The most references made were in relation to stronger group cohesion and team work, better understanding of colleagues, better communication and more tolerance:

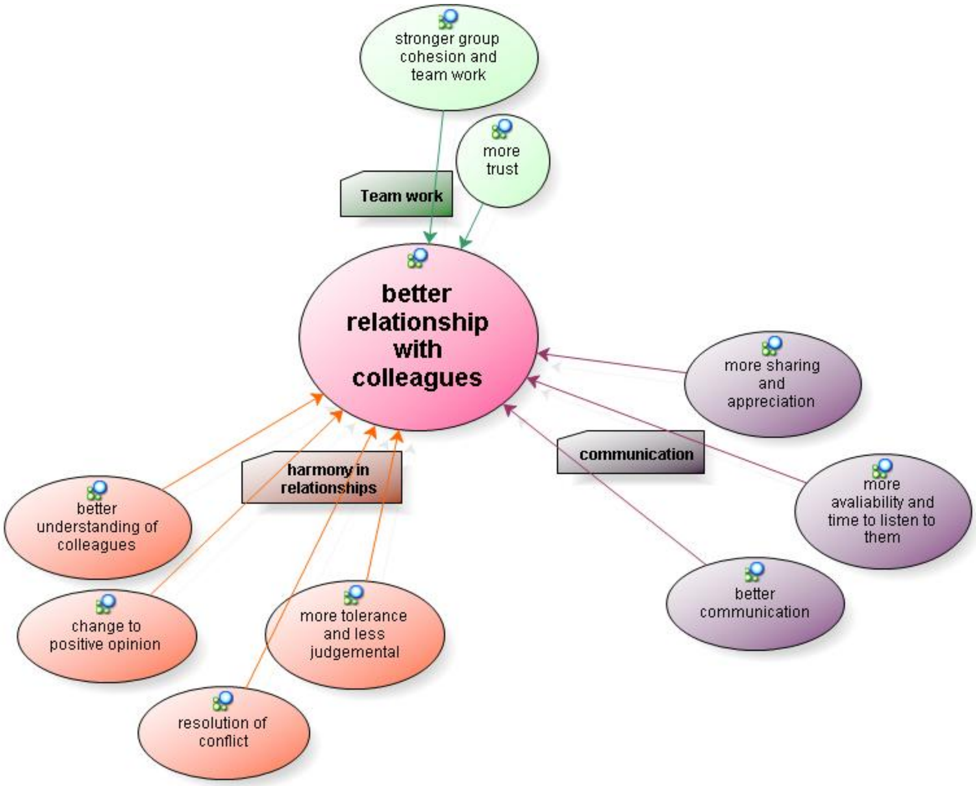


FIGURE 41 - THE RELATIONSHIP WITH WORK COLLEAGUES

Team Work

HCWs found that the therapeutic atmosphere and group work helped them gain more trust in their colleagues and strengthen their group cohesion and team work.

> *"This experience helped me create closer bonds with the people I normally work with, and to understand that it is possible to talk about our difficulties without being afraid of being judged." (Psychologist in PCU: Appendix 21 - 2:4);*
>
> *"…we are a team that have to work towards a common goal, and as a team, we complement each other..." (Nurse in PCU: Appendix 21 - 8:14).*

HCWs commented on how a stronger group cohesion and team work can contribute towards better relationships with the patient and also, how conflicts can decrease efficiency and impact negatively on the relationship with the patient. In the long run, this may also have an impact on levels of burnout:

> *"The course helped to improve my capacity to talk about my feelings and anxieties… to understand the importance of a close relationship with the team in order to improve the relationship with the patient and family" (Nurse in PCU: Ap 17 - 1:6);*
>
> *"...but the relationship that we have in the team also interferes a lot with the way that we deal with the patients…" (Appendix 17 - 1:6);*
>
> *"… (I think that conflicts do affect our work), because it is like this: when we don't feel good, work isn't the same: We are also not well and we can't show that we are. Something fails, we can try to disguise it for a while and for a while we manage but then we don't. …" (Nurse in PCU: Appendix 17 - 1:6).*

Communication

It seems that the open and non-judgemental atmosphere of the intervention encouraged HCWs not only to communicate their feelings and appreciation for each other more openly but also to adopt a more tolerant and understanding attitude towards their colleagues:

> *"I feel more motivated to discuss my feelings and difficulties within the team, without worrying whether they will be accepted or not…" (Nurse in other units: 1:10);*
>
> *"I am more tolerant and listen more to their side" (Nursing aide in PCU: 2:9);*
>
> *"My relationship changed in the sense that I pay more attention to details, I try to be more available and put myself in their place and give them more time to express themselves." (Nurse in other units: 3:9).*

It seems that this had a positive effect on communication skills between colleagues:

> *"In this training, what I learnt is that dialogue is the best way to solve problems, and how important it is for us to feel up to date with ourselves and others" (Nurse in other units: 2:1);*
>
> *"Without doubt, I have become more congruent with my words and when I want to refer efficiently to someone on the team about some incorrect attitude, I do it as adequately as possible. With more tenacity" (Nurse in PCU: 3:18).*

Harmony in Relationships

HCWs commented on how the intervention was useful in getting to know their colleagues at a deeper level, to understand that their attitude can influence positively or negatively relationships with others and this also resulted in more tolerance and understanding:

> *"...the importance of reflecting on my own behaviour, instead of focusing on the behaviour of others. Finding in my behaviour the cause of some behaviours of others..." (Nurse in PCU: 2:2);*
>
> *"…I don't tell people off so much." (Nurse in other units: 1:3);*
>
> *"In the relationship with my colleagues, I try to maintain a good working atmosphere and try not to let myself feel hurt by frictions that exist. I forgive more easily and don't lose time with discussions I understand are not going to get us anywhere." (Nurse in other units: 7:12);*

Occasionally, within the same group, were two colleagues who had some working frictions and the intervention was effective in resolving these issues, although it was not part of the agenda:

> *"...I just felt that it helped me get closer to a colleague, whom up until now, I thought didn't like me much…" (Nurse in other units: 1:13);*
>
> *"In my particular case, it was very useful, because it allowed me to overcome some relationship difficulties I had with a colleague, whom I admire, but with whom I have always had a cold and distant relationship. We got to know each other better, and our relationship is more cordial." (Nurse in PCU: 2:13*).

Comment

What seemed to be appreciated during these six days was the opportunity to see their colleagues from a different perspective. At work, they would wear their professional mask, but here, most of the participants removed their mask and this was seen as most rewarding. It allowed for more understanding, cooperation, tolerance, ability to share difficulties without the fear of being judged, and a few conflicts between colleagues were actually resolved, which could also have a positive effect on burnout. It is quite apparent from these quotes, that benefits were felt both in HCWs in and out of PCUs.

5.2.4 IMPACT ON SELF

When asked about how the intervention impacted on themselves and their private life, participants talked about personal changes, changes in relation to their daily well-being, and improvements in their internal congruence. The most references were made to increased self-awareness and getting to know themselves better, better personal relationships, more self-confidence and assertiveness and more appreciation for life and people.

Personal Changes

(See Appendix 22 – which contains comments on changes in self)

Numerous types of personal changes were mentioned related to personal development, their relationship with others and their capacity to cope with death and dying:

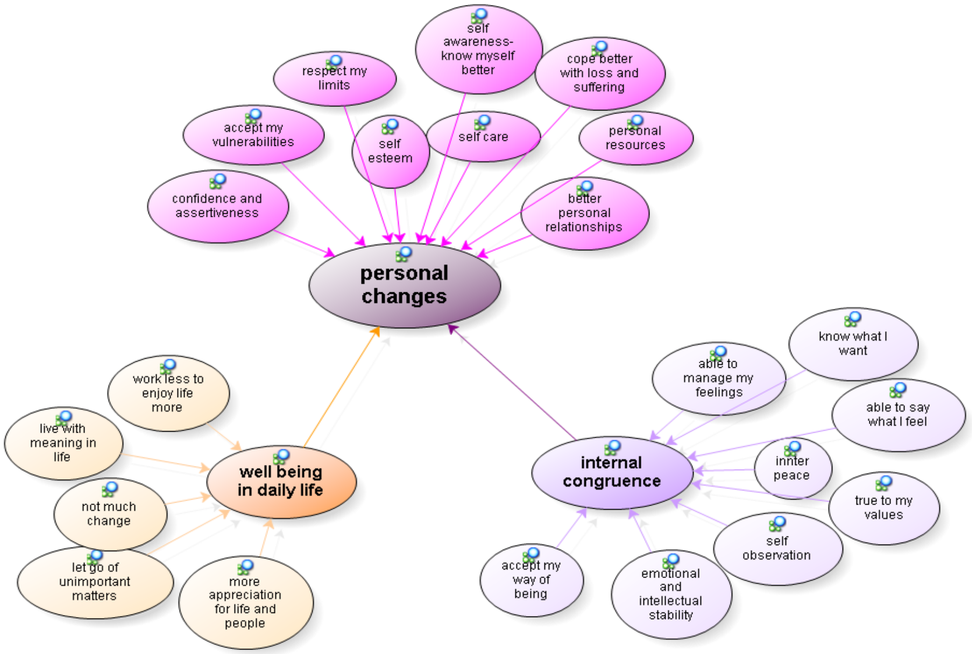


FIGURE 42 - PERSONAL CHANGES

Personal development allowed them to increase their self-awareness, self esteem, confidence and assertiveness. Expressing themselves in a non-judgemental environment and some of the group dynamics performed helped the participants to become more aware of their personal resources to cope with adversities, which gave them more confidence:

> *"The importance of knowing myself so I can manage my feelings" (Nursing aide in other units: 3:5);*

> *"I recognize my own value and feel the same as the others (before, I always felt different) and I understand better my place in the team" (Nurse in other units: 1:8);*
>
> *"I believe more in my capabilities when performing my work" (Nurse in PCU: 4:2);*
>
> *"The most important thing I learnt was getting knowledge on my own potentials as a person and to understand my enormous capacity to face situations of pain" (Social worker in other units: 2:3);*

During the intervention, some time was spent on their habits of self care and time dedicated to family. Changes seemed to have occurred through exercises such as reflecting on the importance of their relationships with loved ones, or understanding that setting time aside for themselves is not being selfish, but responsible, because feeling rested may increase the quality of care to their patients:

> *"My daily life and sense of well-being really got better. Since then, I have organized my work to have more time for me and my family. I have even found time to go to the gym once a week…" (Doctor in PCU: 1:25).*
>
> *"It made me think about life and death on the same level, and that made me find more time for my family" (Nurse in other units: 1:21);*
>
> *"I give a lot of value to my family. Today I find more time to listen to my children and husband, and I see life in a different way" (Nursing aide in other units: 2:21);*

However, even though some changes may have been made, the quantitative results showthat in general, they do not feel that this enough. This can be seen in the factor "Self criticisn for no time for family and meaningful activities", where no significant changes occurred.

HCWs also learned to respect their limits, and accept their vulnerabilities, which may consequently contribute towards reducing burnout:

> *"...becoming aware that nobody can understand and know everything and that so long as we do our best, we do not need to feel guilty or responsible" (Physiotherapist in PCU:4:5);*
>
> *"Professional serenity and knowing and recognizing my limitations" (Nurse in other units: 2:14);*
>
> *"It is a little depressing, at least for a while, because we look inside ourselves and understand our vulnerabilities, and we accept that we are just as fragile as the patients" (Psychologist in other units: 1:18).*

It seems that the intervention also helped them cope with their own personal losses and emotions, which helped them become more empathic with patients and they also felt more mature:

> *"I got to know myself better and it helped me accept certain situations, namely, my mother's death. I can also understand the patients better and accompany them in their process of illness and death" (Physiotherapist in PCU: 2:13);*
>
> *"The course caused an interior revolution in me. I went through a bad phase that brought back feelings of anger, depression and feeling down. But it was the beginning of a change, and I feel more mature to resolve daily situations" (Nurse in PCU: 1:41).*

Internal Congruence

Some comments showed that HCWs felt that there was more harmony within themselves between what they felt, do and said, and this brought them more inner peace and well-being in their private lives, and it seems that this also had a positive effect on their relationship with the patients. This may have been a result of reflecting what they would do if they had little time to live:

> *"Today, more than before the training, I try to be truthful and sincere with myself, I don't try to please others so much when it does me harm…" (Nurse in other units: 1:35).*
>
> *"Some changes in my daily habits, plans and life goals, more congruence between actions and life philosophy. I've created priorities and put into practice a way to carry them out" (Nurse in other units: 2:43);*
>
> *"I feel more free and at peace because I keep the good things and try to let go of the bad. This allows me to be more present with the patient" (Nursing aide in other units: 2:36).*

Well-Being in Daily Life

When talking specifically about feelings of well-being in their daily lives, most HCWs mentioned becoming more aware of the importance of how they live and what kind of attitude to adopt in life, understanding the importance of trying to bring meaning into their personal life. This resulted in living a more balanced life with more time dedicated to family and leisure:

> *"I am still efficient and organized, but now I try not to dedicate too much time to work, in order to have more time for others" (Nurse in other units: 1:26);*
>
> *"I try to make the most of moments of leisure" (Nurse in other units: 2:48).*
>
> *"...it allowed me to give more value to the meaning of life in a way that I hadn't done before, which probably influenced my attitude towards life and other people" (Psychologist in PCU: 1:49);*

Some also mentioned how these same attitudes towards life can be applied at work, and the benefits this brought them:

> *"I am more serene at work; I try to spend the rest of the day more joyfully, because beauty is everywhere. This has brought me a lot of peace, I sleep better and I am not so tired as before." (Nurse in other units: 6:46).*

However, although this was not the case for most of the participants, a few mentioned that no change occurred in their daily life:

> *"In the beginning, I felt a big difference in well-being, and I am sure that it was due to the calming effect of the training, but unfortunately, this effect didn't last for long, and now I worry even more about the death of my loved ones." (Nurse in other units: 1:47);*
>
> *"The course didn't change anything in my daily life" (Nurse in PCU: 2:47);*
>
> *"The course contributed towards talking a lot about people and situations at work, however it didn't change my daily life, my way of working, or myself as a person" (Nursing aide in PCU: 4:47).*

Comment

These changes are related to the exercises and debates that took place during the intervention. Participants had a chance to think about their own personal relationships, and activities in life.

Other exercises focused on finding out what each person's coping strategies were. This not only increased their self knowledge, but also their confidence to deal with future life obstacles. Participants were also able to talk about their limitations as health care professionals, and understand that a failure to cure is not equivalent to being incompetent. They also became more aware of the importance of existing means to enhance the patient's quality of life until death.

Self care was part of the intervention: reflecting on themselves as physical, emotional, spiritual and social beings enabled them to consider whether they were taking steps to care for all these different parts of themselves. Most of the time, this was not the case, and one or more of these areas was discarded, or left as a last priority in a life filled with obligations. However, self care should not be a luxury for HCWs, but an obligation, because this reflects indirectly on the quality of patient care.

Finally, one could also see an improvement in their internal congruence. The intervention did take place in a non judgmental atmosphere, where each person was listened to by the other participants and the facilitator. This gave them the confidence to look at themselves in an honest way, without fear, thereby increasing their self knowledge, self confidence and inner peace.

No significant difference was noted between comments from HCWs in PCUs and in other units, however, the author noted that amongst the elder HCWs, there was an increased need to spend more time caring for their home and loved ones.

5.2.5 GAIN IN KNOWLEDGE

(See Appendix 17 which contains comments showing the relationship that exist between "gain in knowledge" and other areas of work and the resulting consequences).

Analysis of the interviews and qualitative answers also showed that knowledge gained from the intervention had a positive effect or contributed towards other categories of the content analysis, as shown in the following diagram:

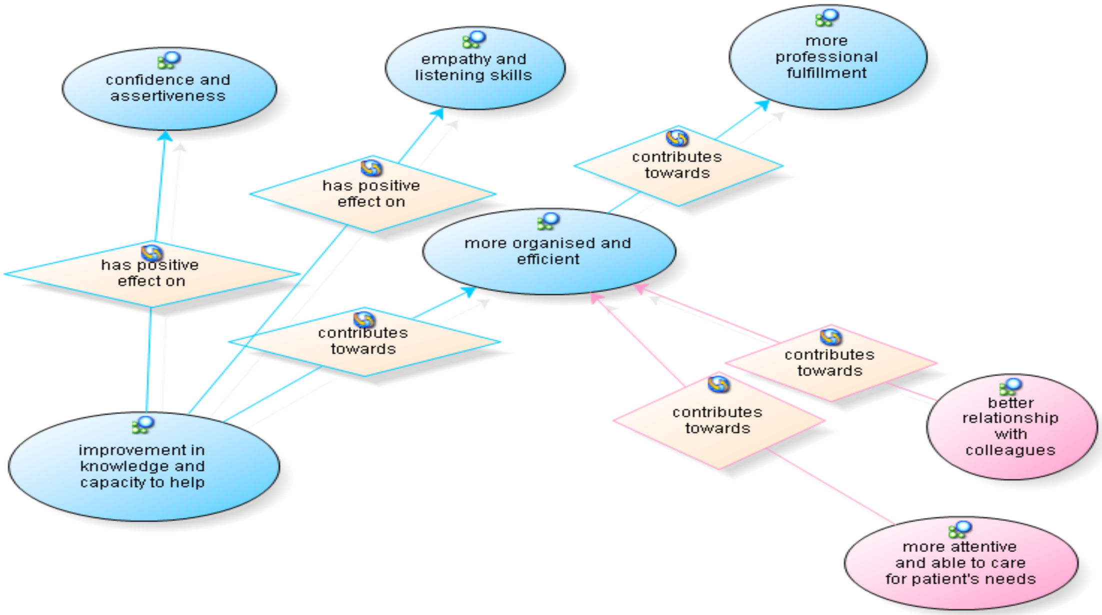


FIGURE 43 - CONSEQUENCES OF GAIN IN KNOWLEDGE

Improvement in knowledge and capacity to help has a positive effect on confidence and assertiveness, empathy and listening as well as having the capacity to help workers become more organised and efficient. HCWs are trained to adopt an active role in health care, and giving emotional and spiritual support was often not considered sufficient. However, once they understood how to provide this type of support effectively, their satisfaction at work increased:

> *"yes, I feel more confident, because you see, I learnt things and I am more attentive to their needs" (Nursing aide in other unit: 1:7);*

> *"I gained more knowledge, and this has helped me to establish a better helping relationship with the patient and family" (Doctor in PCU: 1:1);*

> *"As I understand better the aspects of death etc. I feel that I am more efficient at work" (Psychologist in other units: 2:3).*

HCWs of difierent professions and in and out of PCUs found that being more organized and efficient consequently contributed towards more professional fulfilment, better relationships with colleagues and being more attentive and able to care for patient's needs:

> *"I am more efficient at work because I can and do make a difference and this enables me to grow inside and it gives me a lot of pleasure" (Psychologist in other units: 1:4);*
>
> *"As it improved my relationship with the patients and colleagues, I became more efficient" (Nurse in PCU: 1:4);*
>
> *"I think that being more aware and attentive to certain aspects, I also improved my efficiency as well as being better able to deal with the patient's problems" (not taking them home with me and suffering with them) (Physiotherapist in PCU: 3:4).*

Comment

These results are related to the second part of the course, where practical information was given to the participants about the psychology of patients with a terminal condition, how to help the patient and family from diagnosis to death, how to give spiritual support, as well as practical exercises on person centred counselling. What we can see from these results is that better knowledge and being emotionally capable of applying this knowledge to the benefit of the patient results in more professional fulfilment for the health care worker.

HCWs in other units commented on knowledge learned, which subsequently improved their efficiency and relationship with patients. HCWs in PCUs did not often mention a gain in knowledge, but claimed that the intervention increased their awareness, which in turn increased their efficiency.

5.2.6 NEEDS AND NEGATIVE ASPECTS STILL PRESENT AT WORK

With the purpose of giving the participants the opportunity to talk about what their present needs were and negative aspects about work they felt still needed improvement, participants were encouraged to talk about what they felt still needed to be changed and what they needed in order for this to occur.

Needs

(See appendix 23 for comments regarding needs participants felt were still present after the intervention)

The two most mentioned needs were more training of this type and more group encounters, where they could share feelings and difficulties in a therapeutic environment. In relation to the content of the training they required, most demands were in relation to improving communication within the team.

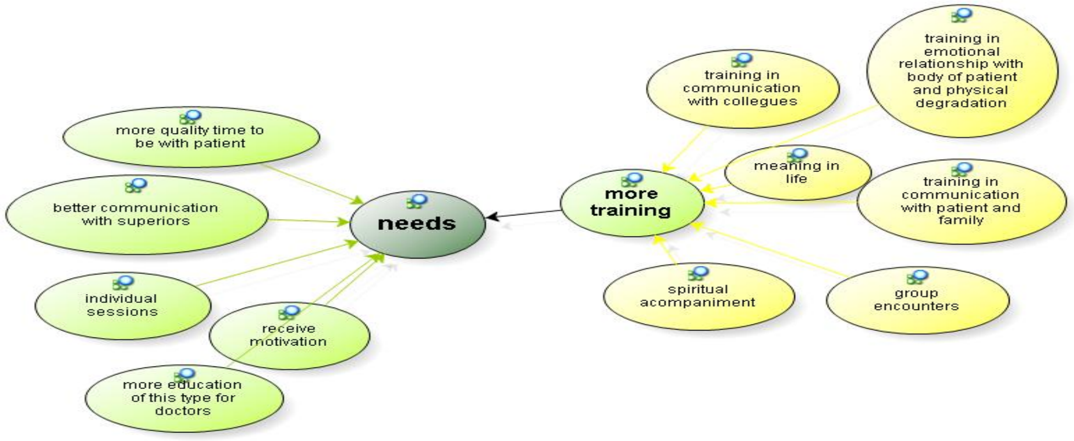


FIGURE 44 - NEEDS STILL PRESENT

In general, most of the people who did the course mentioned the need for continuous training of this sort to get to know themselves better and to improve their care for the patient. Some people also mentioned that they would have liked to have had the opportunity to have individual sessions. (Individual sessions were given by the facilitator when a member of the group was in distress; however, this was not open to everyone on a regular basis):

> *"I think the structure and the content of the course were adequate to the needs, but I am just sorry that we did not have the opportunity for more training in this long journey of self knowledge" (Nurse in other units: 1:1);*
>
> *"I think it would be important to have time for individual sessions and orientation" (Nurse in PCU: 1:4).*

Doctors also valued this training, and thought that more education of this type should be given to them:

> *"I think that people are becoming more and more open to other perspectives and understand that medicine cannot just be scientific issues, and that this type of training is really important" (Doctor in other units: 1:20).*

Health care workers mentioned the need for better communication with their colleagues and superiors, as well as the need to feel appreciated for the good things they do:

> *"...In my opinion, the themes that should be given priority are those related to our emotions and communication difficulties within the team" (Psychologist in PCU: 5:18);*
>
> *Referring to their superiors: "There is one thing that I think is very bad: making decisions that affect the team and the unit, for better or for worst, and not informing anyone" (Nurse in PCU: 1:20);*

> *"I think positive feedback is important, and at this moment, what we hear most is negative feedback" (Nurse in PCU: 1:22).*

Finally, the health care workers were saddened by the fact that there were too few nurses for the amount of patients, and this reduced their quality time with the patients to almost nothing, and the nurses working in palliative care units were particularly upset, because they had chosen to work in palliative care, specifically so that they could give quality care to the patients.

> *I would like to have more time to spend with the patient (Nurse in PCU: 1:2).*

<u>Negative Aspects Still Present at Work</u>

(See Appendix 24 for comments on negative aspects still present and Appendix 17 for comments showing signs of burnout)

The negative aspects still present were divided into three main categories, communication difficulties, burnout and emotional difficulties:

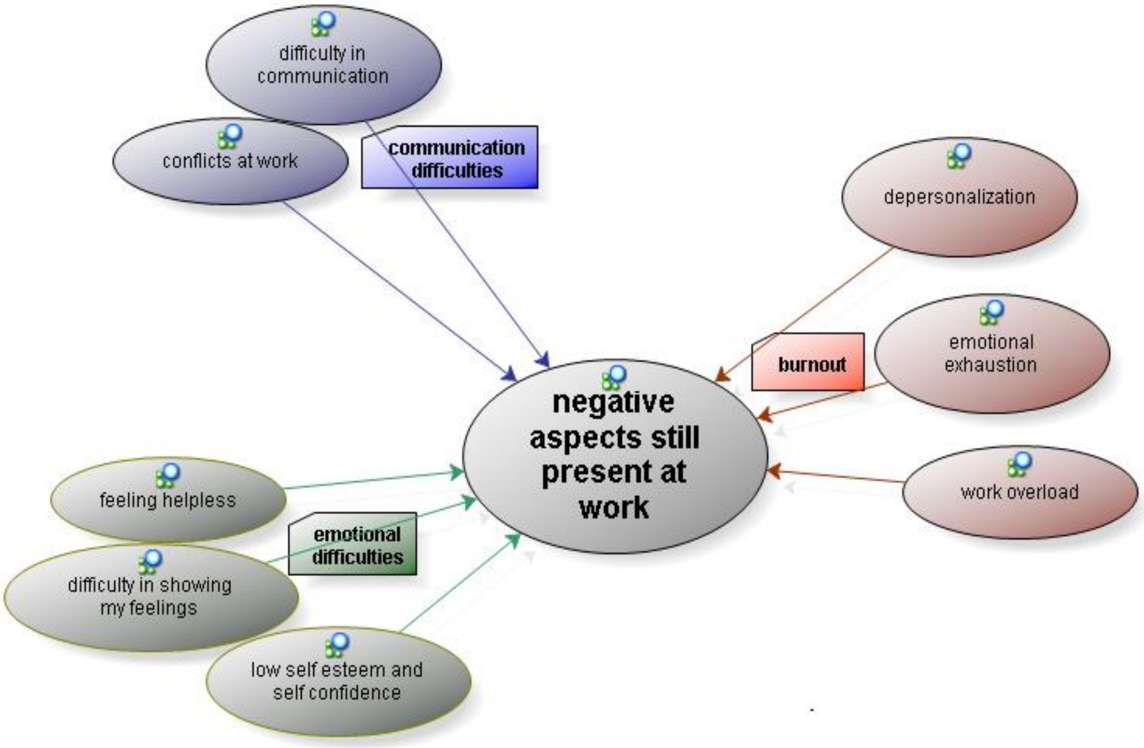


FIGURE 45 - NEGATIVE ASPECTS STILL PRESENT AT WORK

Communication Difficulties

Although the majority gained confidence in their capacity to communicate with patients and their family, some participants still showed some insecurity, especially nursng aides from other units:

> *"…but I still have difficulty in certain situations, of not knowing what to say" (Nursing aide in other units: Appendix 24 - 1:1);*
>
> *"...and then, in relation both to the patient and family, I can never say something at the right time…" (Nursing aide in other units: Appendix 24-1:4).*

It also seems that conflicts at work were a significant problem, because these seemed to persist, or return. The intervention did not have any long-term effect in improving conflicts within the team:

> *"...in relation to the other elements of the team, I have noticed a distancing (which has nothing to do with the groups created in the course), that comes as a consequence of each person's own ambitions." (Nurse in PCU: Appendix 24-1:2);*
>
> *"...at the time, I thought that the relationships within the team improved, because we were going through a bad phase with a lot of conflicts, and things did get better. Now, I think they have got worse again." (Nurse in PCU: Appendix 24-3:3).*

Burnout

Although the results of the quantitative data showed that overall levels of emotional exhaustion were below the cut-off line, the qualitative data showed otherwise. As suggested in the literature review, this study confirmed that work overload was mentioned as a significant cause for feelings of burnout by health care workers in different professions. However, some comments were made that showed that some HCWs found that being constantly around death was also tiring:

> *"...we are few for nearly the same volume of work…and then there are holidays, where people come and go….and it has given me a big volume of patients…..and I have had many medical consultations to do…and one must become alienated to small details. At the end of the day, I just want to go home…." (Doctor in PCU: Appendix 24-1:5);*
>
> *"…when that happens I feel tired and sad, because we give a lot of ourselves…this story of giving without wanting anything in return is not true, it doesn't work with me, because I don't think anyone gives without expecting anything at all in return. At least, recognition of our work…when we don't get this, we feel very demotivated….." (Nurse in other units: Appendix 24-2:4);*
>
> *"I don't know if it is because we deal a lot with death or if it is the people who have been here for a long time, and are tired ….." (Nurse in PCU: Appendix 24-3:4).*

Likewise, the overall quantitative results of depersonalization were very low in the quantitative data, but the qualitative data from the interviews showed some examples of the presence of feelings of depersonalization:

> *"We do give, but it is almost a routine...talking to the patient…that's all fine, but there is something missing…everything is so mechanical…." (Doctor in PCU: Appendix 24-1:3);*
>
> *"You're there with the patient, and sometimes it takes a whole hour to understand something small, and sometimes I have to say "yes, yes, ok"…so that things get going a bit." (Doctor in PCU: Appendix 17 - 1:9).*

Some comments also showed burnout in terms of decreased efficiency:

> *"I'm tired. Sometimes you feel a little run down, because it is always the same thing, see the patient, see the patient, and you don't have time for anything else…and you just get a bit….you don't pay so much attention. Lots of times I am on my way home and I think "I forgot to do this….I was asked to do that, and I forgot…." (Doctor in PCU: Appendix 17 - 1:8);*
>
> *"...in terms of efficiency, things are the same. Some things can't be changed with the course, because they have to do with the need for more health care workers…" (Nurse in PCU: Appendix 24-1:3);*
>
> *"The volume of work to do fills our head up in such a way, that we have to just do what is most urgent, and you lose that sense of well-being that would lead us to do that bit extra…" (Doctor in PCU: Appendix 17 - 1:9).*

Emotional Difficulties

HCWs also mentioned some emotional difficulties they were still trying to cope with, such as feeling helpless, showing their feelings in front of the patients and lack of self esteem.

> *"There are still some hesitations in relation to what to say and how to approach the family. I still feel "weak" when facing dramatic situations, when I would like to do something, and can't…" (Nursing aide in other units: 2:1);*
>
> *"I still need to improve a bit in showing my feelings..." (Nurse in other units: 1:1);*
>
> *"I still feel inferior, because the team has knowledge that I don't think I will be able to acquire…" (Nurse in other units: 1:5).*

Comment

Difficulties were still present within the participants when questioned between four and seven months after the training. Mainly, these had to do with burnout, emotional difficulties and communication difficulties within the team. Burnout was due mainly to work overload, which led to the other difficulties of emotional exhaustion and depersonalization. These problems of work overload are not easily overcome, and the intervention tried to focus on the needs of the group and the system as a whole rather than focusing on just one aspect. The intervention allowed for: communication within the team, time to talk about self, time to think about their private lives and ways to improve the relationship with the patient and family within the little time available.

Some differences were present within HCWs in other units and HCWs in PCUs. With regard to negative aspects still present in communication, HCWs in other units mentioned still having some difficulties in knowing what to say to patients. HCWs in PCUs however, focused more on communication difficulties within the team. With regard to burnout, work overload was mentioned by HCWs from both groups. However, with regard to emotional exhaustion and depersonalization, although both groups commented on tiredness and exhaustion, HCWs from PCUs were particularly upset, because they had chosen to work in PC specifically to be able to provide better quality care to the patients, but due to lack of personnel, this was not happening.

5.3 COMPARISON OF QUANTITATIVE AND QUALITATIVE RESULTS

The open ended questions and interview questions were designed to evaluate not only the impact of the intervention on their personal well-being, the quality of their helping relationship and their sense of well-being at work, but also to evaluate the course itself. As a consequence, not all of the qualitative data could be compared to the quantitative data. More specifically, feedback concerning the intervention itself is not comparable. However, some of the questions related to the helping relationship with the patient and family and others related to personal well-being are comparable.

The first section shows a comparison of quantitative and qualitative results from before the intervention and the post-intervention sections have been reorganised to group together comments that fall under the operational hypotheses. This was found to be the easiest way to understand how the qualitative findings back up the quantitative results and simultaneously show how the hypotheses are supported.

5.3.1 PRE INTERVENTION COMPARISON OF QUANTITATIVE AND QUALITATIVE DATA

Quantitative data regarding difficulties (questionnaire items)	Qualitative data supporting quantitative data (Appendix 16)
Avoidance mechanisms	
Fear of not being able to cope with all of the patient's fears and anxieties: I tend to put on a role or front with them I don't show my inner impressions and feelings with them It bothers me when they try to talk about certain	"I am afraid of getting involved with the patient, so I put on a mask, but I fear that this mask is spreading to my private life". (3:1) (in other unit) "I avoid looking them in the eyes when I don't want to talk…." (10:1) (in other unit)

Boundaries and feelings of helplessness	
It is not easy for health care workers to accept their limitations, and that death is not a failure of medicine: I feel helpless when faced with the patient’s fragility I ask myself many times if I could have “done more” and this makes me feel anxious	“I take problems home. I feel it is my duty to alleviate the weight of their suffering” (2:3) (in PCU) Suffering with their suffering: what do I do? What I do is not enough...” (6:3) (in PCU)
Dealing with suffering	
Bereavement: I am emotionally disturbed by the death of so many patients **The meaning of suffering:** The time of dying has no value. It is best to die quickly to end the suffering Without physical health, it is not worth living	“I need an interval between patients to recompose”(2:9); (in other unit) “Bereavement: we feel that we have to get over the patient’s death quickly” (11:9). (in PCU) “feelings of anger and injustice over so much suffering” (4:9); (in other unit) “It is better to die than to suffer. What is the meaning of suffering? (25:9) (in PCU)
Conspiracy of silence	
Being afraid that the conversation may harm the patient was expressed: Dealing psychologically with terminally ill patients makes me feel insecure and anxious	“How far can I go when talking to the patient – I am scared of doing them harm” (3:26). (in PCU) “Having to hide my feelings in front of the patient” (afraid that showing any sign of worry, that they will be harming the patient) (15:26).(in other unit)
Communication difficulties	
Feelings of incongruence: There are times when my outward response to them is quite different from the way I feel underneath **Unconditional acceptance:** The interest I feel in them depends on their words and actions Depending on their actions, I have a better opinion of them sometimes than I do at other times If they get impatient or mad at me, I become angry or upset too The relationship with the patient’s family wears me out	“Giving bad news….. I really feel their pain, but I don’t know what to do or say, so I avoid them, and am then seen as cold” (3:3); (in PCU) “When the patient’s look is one of pain, we help, but if it is a look of superiority, we take a step back. It is difficult to be tolerant when they look at us with hate. It is also difficult to accept drunks and drug addicts.” (1:26); (in other unit) “When the family is aggressive with the unit” (2:6); (in PCU)

TABLE 39 - COMPARISON OF QUANTITATIVE AND QUALITATIVE DATA RELEVANT TO HYPOTHESIS 1

When ordering difficulties by where HCWs worked: in PCUs or in other units, results showed the following:

HCWs in PCU	HCWs in other units
Avoidance Mechanisms	
"…facing the families' reaction when the patient dies. I don't know what to say, so I avoid them." (5:1)	"I avoid looking them in the eyes when I don't want to talk….". (10:1)
"It is difficult to accept death and suffering, so I defend myself by avoiding the patient…..but then I suffer anyway, because I feel I haven't helped the patient" (4:1)	"I am afraid of getting involved with the patient, so I put on a mask, but I fear that this mask is spreading to my private life". (3:1)
Boundaries	
"I take problems home. I feel it is my duty to alleviate the weight of their suffering" (2:3)	
Suffering with their suffering: what do I do? What I do is not enough..." (6:3)	
"I suffer a lot with the families, because I have been through the same thing" (4:1)	
"Creating bonds with young patients and then losing them"; (16:1)	
"Caring for family members that are my age" (17:1).	

Dealing with suffering	
“Bereavement: we feel that we have to get over the patient’s death quickly” (11:9).	“I need an interval between patients to recompose”(2:9);
“It is better to die than to suffer. What is the meaning of suffering? (25:9)	“feelings of anger and injustice over so much suffering” (4:9);
“Dealing with parents losing their children” (6:9);	“Problems with the physical degradation of patients: it is ok if they are still full of hope, but I don’t know what to do when they relapse and loose hope. I feel bad, because I know them well, and I really want them to get cured” (17:11);
“Accepting death in young people: talking to a young father or mother who is dying, and talking to their family” (32:9).	“Dealing with physical pain when doctors won’t collaborate to reduce their pain. It happens a lot because they think that giving pain medication will accelerate their death” (20:11);
“Listening to patients moan” (24:12).	
Separation and death anxiety	
“Understanding and accepting death…difficulty with separation, even though I believe in life after death, in reincarnation and that we come here with a purpose…” (1:23)	“I find it very difficult to talk about death because I am scared of it” (3:23)
“Preparing the corpse – the person is cold” (9:23) (preparing the corpse was also mentioned by HCWs in other units)	“Thinking that there is nothing after death” (5:23)
	“Taking the patient to the mortuary – it gives me the creeps” (7:23)

What to say, conspiracy of silence	
"How far can I go when talking to the patient – I am scared of doing them harm" (3:26).	"Having to hide my feelings in front of the patient" (afraid that showing any sign of worry, that they will be harming the patient) (15:26).
"Answering difficult questions. How to not take away hope, but not create illusions? (22:26);	"Defence attitudes that end the conversation. We still say things like "Never mind, I am worse off than you are today!" (said in a playful way), or "We are all going to die one day. I might even go before you" (9:26);
	"Feeling helpless leads us into this. For example, one patient was being transferred to the ICU and the nurse said – 'See you when you get back' - and the patient answered –'Thank you for everything you have done. I'm going to die' -. It was terrible for them, and they didn't know what to say." (16:26);
	"I know all the theory, but I do it anyway, because I am very aware of what is coming" (18:26).
	"How can I talk about death when it is not imminent?" (11:26);
	"What do I say when they start talking about death?" (12:26).
Feeling helpless	
"Knowing what the person needs to die in peace and not being able to do anything about it" (3:14);	"Waiting for the end – feeling helpless for not being able to do anything" (34:14);
	"What to do in the end when there is no cure: Feeling helpless and as if I have failed" (7:14);
	"What do I say when the patient says "Don't let me die?" (8:14)
Capacity to empathize and communicate this to patient	
"Really understanding them, and their expectations" (1:21).	(Author's note): "I noticed some tendency to treat the elderly as children. The health care workers talked about caressing the elderly person's cheek and being rejected and not understanding this aggression. However, from the way this was described, the way they addressed the person, was as if he were a child". (1:17)
"Giving bad news….. I really feel their pain, but I don't know what to do or say, so I avoid them, and am then seen as cold" (3:3);	

Unconditional acceptance	
“Judging family members who never visit” (2:26).	“When the patient’s look is one of pain, we help, but if it is a look of superiority, we take a step back. It is difficult to be tolerant when they look at us with hate. It is also difficult to accept drunks and drug addicts.” (1:26);
“When the family is aggressive with the unit” (2:6);	“What to do when the family “suffocates” the patient” (3:6);
Internal congruence	
“Feeling helpless when communicating with someone who can no longer talk” (6:6).	“...what bothers us is the indifferent look: there is no psychological interaction even though we try. The person has given up, and we don’t know how to reach them” (2:8);
“...difficulty with direct questions such as ‘Do I have cancer?’” (3:17)	“Communicating when the patient doesn’t talk, either because he is too sick, or because he doesn’t want to.” (3:8).
“...unpredictable situations of intimacy” (1:17).	“...difficulty when talking about emotional or spiritual matters” (5:17).
Emotional incongruence	
“Not being understood at home, so I take refuge in my work colleagues” (1:20)	"body language: the truth comes out when I am not feeling congruent” (2:7);
“The patient died before I said goodbye. It’s stuck in my throat” (1:21).	“Internal incongruence when trying to hide from the patient what I feel” (3:7).
“I find it difficult to create diets for terminal patients, because I feel as if I am giving up on them” (1:22);	“vomit” (1:13);

"How do I give quality time with no time?" (2:19);	"Difficulty with certain smells, to the point of sometimes having to leave the room" (4:13).
	"How not to make a face when the wound is very ugly; Pretending creates awkwardness" (2:13);
	"I can only accept chocolates from a patient if I know them well and feel affection" (3:13);
	"…Giving bad news when there is no cure and talking of death. I tend to run away from the patient because I can't cure them, and I feel that I have let them down. And then I feel guilty for running away" (1:16).
	"Difficulty to accept our limitations. When must we stop treatment? I feel as if I am giving up on the patient" (2:22);
	"Dealing with the families and the transition from curative to palliative" (3:22);
	"What to do when the doctor wants to continue curative treatment until the end?. Nurses are divided because they also feel lost when they understand there is no cure, but at the same time, to continue to treat the patient with aggressive treatments is violent, because as nurses, we are trained to care for the well-being of the patient, and giving chemotherapy to a dying patient is not giving well-being" (6:22).
	"I know that presence can help to alleviate pain, but in our unit, where there is no time, this is utopia. As there is no time to talk to the patient, when I understand that the patient wants to start a conversation, either I leave the room, change the subject or don't answer" (3:19).
Team and workplace	
"I feel pressured from all sides" (1:30);	"Many internal difficulties, conflicts and inflexibility on behalf of the chief" (2:7).
"Leaving work tired and frustrated" (1:14).	"Patients are put behind the curtain when they are dying so as not to upset the other patients. When I talk to the doctors about this, they say "You're still young". This upsets me" (2:21).
"Managing time (guilt: trying to manage work and family not understanding) (1:25);	"Dealing with the expectations of workers who ask for help" (1:18);
"Feelings of anger for not being able to find time to be with the patient" (2:25);	"showing our vulnerabilities" (2:24);

"Feeling incongruent when I feel I should stay but am being pulled to leave by another person or patient" (3:25)	
"Lack of time: if we go home on time to be with the family and have a balanced life, we are overloading the next shift" (3:25);	
"Colleagues not being direct. Gossip" (1:7);	
"Lack of team meetings; there is no time to talk" (1:19).	
"The image people have of palliative care: the place where you go to die. Some people even think that the patients are tidied away on shelves waiting for death. How do we re-educate them?" (1:17).	
"Feeling unappreciated by superiors" (1:21);	
"The isolation of being chief" (2:18)	
"Feeling ashamed: he who cries is weak" (3:24).	

TABLE 40 - COMPARISON OF HCWS IN PCUS AND HCWS IN OTHER UNITS

Overall, difficulties were similar in both groups. Difficulties with boundaries seemed to be more present in HCWs in PCUs and were related to feeling that what they did to alleviate the weight of suffering was not enough, and creating bonds with patients. Infantilizing patients was a characteristic that was noticed in HCWs with no PC training. With regard to emotional incongruence, difficulties in HCWs in other units were mostly related to difficulty in accepting that there is no cure, and issues of physical degradation in patients, whereas in HCWs in PCU, emotional incongruence was mostly related to not being able to give the quality of care they desired.

5.3.2 HYPOTHESIS 1

There would be an improvement in the levels of HCWs' personal well-being and perception of their competencies in helping relationship skills.

With the exception of the factor "no time for family and meaningful activities", the quantitative results supported Hypothesis 1, that there would be an improvement in the levels of HCWs' personal well-being and perception of their own competencies in helping relationship skills. Analysis of the qualitative results shows that these are in agreement with both the hypothesis and the quantitative data:

Quantitative data supporting hypothesis (questionnaire items)		Qualitative data supporting hypothesis
Increased self-confidence, dignity and meaning when faced with adversity and illness		Appendix 22 -Personal changes
Some items relating to Capacity to cope with pain and suffering and the unknown	I trust that when the time comes, I will receive what I need to deal with my physical pain Deep down, I know that I can tolerate more physical pain than I think I feel I have strategies and inner strength to deal with unforeseen situations that appear in my life I face challenges with quite a lot of internal confidence	"the most important thing I learnt was getting knowledge on my own potentials as a person and to understand my enormous capacity to face situations of pain" (2:3) (in other units); "Know how to be and act in situations that I had difficulty in" (1:2) (in other unit);
Some items relating to Meaning in life in spite of illness	In spite of the physical pain that I may suffer from, life will continue to have meaning I accept that physical pain, like any other, is part of life, whether it is my pain or other people's pain I accept difficult situations as part of my life journey and personal growth My dignity does not depend just on my usefulness in society	"Professional serenity and knowing and recognizing my limitations" (2:14).(in other unit); "...becoming aware that nobody can understand and know everything and that so long as we do our best, we do not need to feel guilty or responsible" (4:5) (in PCU);
Some items relating to Acceptance of oneself and of natural aging	I feel the same person, even when I am not happy with my physical appearance I can accept aging and the gradual degradation of my body as a natural stage in life Apart from my physical aspect, I also value the emotional and spiritual side of me	No comments made
Increased close Personal Relationships and meaning in life		Appendix 22 -Personal changes
Some items relating to Close	I make a point of finding time in my life to be with friends I have many real friends whom I can	"It made me think about life and death on the same level, and that made me find more time for my

personal relationships	count on I normally phone friends and family, just to see how they are I normally tell people I love what they mean to me	family" (1:21) (in other unit); "I give a lot of value to my family. Today I find more time to listen to my children and husband, and I see life in a different way" (2:21) (in other unit;
Some items relating to Meaning in life	I find ways to feel fulfilled in everyday life Right now, I think that my life has meaning	"..it allowed me to give more value to the meaning of life in a way that I hadn't done before, which probably influenced my attitude towards life and other people" (1:49). (in PCU); "I am more serene at work, I try to spend the rest of the day more joyfully, because beauty is everywhere. This has brought me a lot of peace, I sleep better and I am not so tired as before." (6:46). (in other unit);
Some items showing no change	I am always in a hurry and do not always notice or thank the caring gestures of other people I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life I often do not show my appreciation to friends and family, and then regret it There is no balance in my life between obligations and leisure I spend a lot of time doing activities I do not like	However, not all HCWs showed change: "In the beginning, I felt a big difference in well-being, and I am sure that it was due to the calming effect of the training, but unfortunately, this effect didn't last for long, and now I worry even more about the death of my loved ones." (1:47) (in other unit); "The course contributed towards talking a lot about people and situations at work, however it didn't change my daily life, my way of working, or myself as a person" (4:47) (in PCU);
Reduced fear of dependence, physical degradation and loss of control		Appendix 22 -Personal changes
Items relating to fear of dependence and physical degradation	If I become ill, I would rather die than become dependent on others The time of dying has no value. It is best to die quickly to end the suffering If I cannot be an active and independent person, my life would lose all meaning Physical degradation frightens me. It makes me feel reduced to nothing If I have to die, may it be quick I would rather die than be in physical pain	"It is a little depressing, at least for a while, because we look inside ourselves and understand our vulnerabilities, and we accept that we are just as fragile as the patients" (1:18) (in other unit);

Items relating to fear of loss of control	I am not at ease until have everything "under control" I do everything I can to avoid any difficulties or instabilities in my life I feel the need to be informed of everything that surrounds me	“...becoming aware that nobody can understand and know everything and that so long as we do our best, we do not need to feel guilty or responsible” (4:5);(in PCU) “Professional serenity and knowing and recognizing my limitations” (2:14). (in other units);
Increased empathy towards Patient and Family		Appendix 19 –Relationship with Patient Appendix 20 – Relationship with Family
Some items relating to Empathy	Capacity to empathize I usually can tune in and understand all of their meaning I can tell what they mean, even when they have difficulty saying it. I appreciate just how their experiences feel to them I usually sense or realize how they are feeling	“I understand how much they are suffering with what they are going to lose. I am more empathic….” (3:8) (in other unit) ; “The sharing of experiences of different people, of different professional groups helps to understand the problems that can occur at the end of life.” (5:1) (in other unit); “Even though I think that in general I have a good relationship with the patient and family, I am more aware and sensitive to details that before, would just pass me by” (17:1) (in PCU;
Some items relating to difficulty in empathizing	At the time I don't realize how touchy or sensitive they are about some of the things we discuss I hear their words but don't know how they feel inside	
Increased congruence within the helping relationship		Appendix 19 and 20 –Congruence in helping relationship
Some items relating to Congruence	Congruence: I am able to be openly myself in our relationship, without hiding my vulnerabilities I feel that I am genuinely myself with them. I know exactly what I feel in relation to them. I don't sense anything that's hard to face and admit to myself I don't avoid or put off dealing with anything that matters between us.	“Before, I was afraid to approach the family with certain subjects, because I always thought they would blame us when things didn’t go well….” (1:31). (in other unit); “The relationship with the patient improved, because the course helped me to accept that suffering is part of life, and this allowed me to stop running away or avoid talking about these things with the patient” (4:11) (in other units); “Authenticity and honesty that we talked about in the course are essential to be able to help the patient and family get through this period of their lives.” (1:7) (in PCU);
Some items relating to avoidance mechanisms	There are times when my outward response to them is quite different from the way I feel underneath It bothers me when they try to ask or talk about certain things I don't show my inner impressions and	

	feelings with them I tend to put on a role or front with them	
Increased unconditional acceptance and positive regard with patient and family and reduced distance and impatience		Appendix 19 –Relationship with Patient Appendix 20 – Relationship with Family
Some items relating to Unconditional acceptance	Unconditional acceptance Whether they are expressing "good" thoughts and feelings, or "bad" ones, does not affect the way I feel towards them The way I feel about them doesn't depend on their feelings towards me My liking or disliking of them isn't changed by anything they say about themselves I don't think that particular things they say or do alter the way I feel towards them Whether they are feeling happy or unhappy with themselves doesn't make me feel more or less positive towards them	"I learnt to listen, respect, not judge and accept" (2:5). (in other unit); "It made me rethink about the blame I put on certain families and the difficulty I have in forgiving them. Now I look at the good things they have and try to forgive" (1:8) (in other unit); "I have more respect for the families' feelings. Before the training, I wanted to impose my way of thinking, and today I understand that it is all a question of time and maturing" (6:8) (in other unit); "I am more tolerant when the family talks to us aggressively, as a result of their anger" (7:9). (in PCU);

TABLE 41 - COMPARISON OF QUANTITATIVE AND QUALITATIVE DATA RELEVANT TO PRE-INTERVENTION DIFFICULTIES

5.3.3 HYPOTHESIS 2

An intervention that addresses personal well-being and helping relationship skills will reduce burnout

The following table is divided into two parts:

- Items from the quantitative data are contrasted with the qualitative data to facilitate understanding of what continues to be the causes of burnout. The quantitative results show results below the cut-off point (3.69) for emotional exhaustion (M=2.89 at T2), but this does not mean that emotional exhaustion is not present. Likewise, levels for depersonalization are extremely low (M = 1.63), but the qualitative data shows ways in which depersonalization can still be present.
- The second part shows comments from the qualitative data that show the relationship between burnout and the relationship with the patient and between the consequences of

burnout on work efficiency and well-being. This implies that if these issues are addressed, levels of burnout should be reduced.

Quantitative data (questionnaire items)		Qualitative data
Reduced levels of emotional exhaustion		Appendix 24 –Negative aspects still present
Some items relating to emotional exhaustion show relatively low levels in the quantitative data, but qualitative data shows otherwise:	I feel emotionally drained by my work I feel worn out I have no strength left at the end of a day's work I feel that I work too hard in my profession I feel frustrated by my work I am frustrated because I cannot find the time to have a quality relationship with the patient	“...we are few for nearly the same volume of work…and then there are holidays, where people come and go….and it has given me a big volume of patients…..and I have had many medical consultations to do…and one must become alienated to small details. At the end of the day, I just want to go home….” (1:5) (in PCU); “I think people are saturated” (1:4) (in PCU);
Reduced levels of depersonalization		Appendix 17 - Burnout
Some items relating to depersonalization also show low levels in the quantitative data, but qualitative data does show some signs of saturation leading to depersonalization	I have become more insensitive to people since I have this job I give more importance to the technical part of my work than to the human part I give a lot of importance to treating the illness, but do not have patience for the psychological and spiritual caring of the patient Working everyday with people is a real burden for me	“We do give, but it is almost a routine...talking to the patient…that’s all fine, but there is something missing…everything is so mechanical….” (1:3) (in PCU); “You’re there with the patient, and sometimes it takes a whole hour to understand something small, and sometimes I have to say “yes, yes, ok”…so that things get going a bit.” (1:9) (in PCU);
Increased Professional fulfilment		Appendix 24 –Negative aspects still present Appendix 17 - Burnout
Some items relating to professional fulfilment that show contradicting results with qualitative data	I often contribute towards giving my patients quality of life, comfort and dignity at the end of their life I feel that what I do makes a difference I have accomplished many useful things in this work I feel energetic I manage to find time in my work to talk to patients and to help them find meaning in their lives I feel fulfilled at work because I manage to find time to just "be" with the patient and their family	Appendix 24 “…when that happens I feel tired and sad, because we give a lot of ourselves…this story of giving without wanting anything in return is not true, it doesn’t work with me, because I don’t think anyone gives without expecting anything at all in return. At least, recognition of our work…when we don’t get this, we feel very demotivated…..” (2:4) (in other unit); “...in terms of efficiency, things are the same. Some things can’t be changed with the course, because they have to

		do with the need for more health care workers…" (1:3) (in PCU); Appendix 17 "I'm tired. Sometimes you feel a little run down, because it is always the same thing, see the patient, see the patient, and you don't have time for anything else…and you just get a bit….you don't pay so much attention. Lots of times I am on my way home and I think "I forgot to do this….I was asked to do that, and I forgot…." (1:8) (in PCU); "The volume of work to do fills our head up in such a way, that we have to just do what is most urgent, and you lose that sense of well-being that would lead us to do that bit extra…" (1:9) (in PCU);
Burnout versus relationship with patient, well-being.and work efficiency		
Qualitative data showing the relationship between burnout and helping relationship skills and personal and professional well-being	Work overload affects the quality of their attitudes towards patients: "The volume of work to do fills our head up in such a way, that we have to just do what is most urgent, and you lose that sense of well-being that would lead us to do that bit extra…" (1:9) (in PCU); Conflicts at work impact on the relationship with patient: "...but the relationship that we have in the team also interferes a lot with the way that we deal with the patients…" (1:6); Work overload also contributes towards decreased efficiency : "I'm tired. Sometimes you feel "a little run down, because it is always the same thing, see the patient, see the patient, and you don't have time for anything else…and you just get a bit….you don't pay so much attention. Lots of time I am on my way home and I think "I forgot to do this….I was asked to do that, and I forgot…." (1:8) (in PCU); Conflicts at work contribute towards decreased efficiency: "…I think that conflicts do affect our work, because when we don't feel good, work isn't the same…" (1:6) (in PCU);	

TABLE 42 - COMPARISON OF QUANTITATIVE AND QUALITATIVE DATA RELEVANT TO HYPOTHESIS 2

5.3.4 HYPOTHESIS 3

An increase in sense of personal well-being and a reduction in death anxiety will improve perception of competency in helping relationship skills

The following table shows some items related to personal well-being and death anxiety, and the comments were chosen to particularly reflect how a reduction in death anxiety can improve patient care, as suggested in hypothesis 3.

Quantitative data supporting hypothesis (questionnaire items)		Qualitative data supporting hypothesis
Increased levels of personal well-being		Appendix 17
Some items related to personal well-being:	Apart from my physical aspect, I also value the emotional and spiritual side of me I face challenges with quite a lot of internal confidence I feel fulfilled in my profession I find ways to feel fulfilled in everyday life	"I feel more free and at peace….This allows me to be better with the patient" (1:5) (in other units);
Reduced levels of death anxiety		Appendix 17
Some items relating to death anxiety	In spite of the physical pain that I may suffer from, life will continue to have meaning. I feel I have strategies and inner strength to deal with unforeseen situations that appear in my life I can accept aging and the gradual degradation of my body as a natural stage in life	"…if we accept death better, and that the patient is here to die, but with more quality of life and less suffering…maybe we will be capable of caring for them differently…not that before we cared for them badly, …we gave the best technically…but perhaps in terms of relationships, we can help the patient in a different way" (1:7) (in PCU);

TABLE 43 - COMPARISON OF QUANTITATIVE AND QUALITATIVE DATA RELEVANT TO HYPOTHESIS 3

A comparison of HCWs in and out of PCUs after the intervention showed some differences.

- HCWs in other units valued new knowledge they had acquired, whereas those in PCUs claimed that most of the knowledge was not new, but that they had become more aware, and this had improved the quality of care and had increased their efficiency.
- HCWs in other units mentioned that they still had some communication difficulties in relation to what to say to patients, whereas HCWs in PCUs mentioned more communication difficulties within the team.
- Work overload was an issue for HCWs both in and out of PCUs, however, those in PCUs seemed more upset with the fact that lack of personnel and work overload was an impediment to good palliative care.

5.4 **CHAPTER SUMMARY**

The results largely support the hypotheses as shown in section 5.

1. There was an improvement in the levels of HCWs' personal well-being and perception of their own competencies in helping relationship skills:

With the exception of "self criticism regarding no time for family and meaningful activities", which was shown to be related to work overload, all the factors related to personal well-being and perception of helping relationship skills showed significant improvements in the experimental groups and no change in the control group. In particular:

- HCWs from PCUs showed the most improvement in "fear of dependence, physical degradation and loss of control" and those in other units showed the most improvement in "self-confidence, dignity and meaning in life in spite of adversity and illness".
- HCWs in other units made significantly more progress in "empathy and congruence" than HCWs from PCUs.
- After the intervention, HCWs over 30 made more progress in "empathy and congruence" and "fear of dependence, physical degradation and loss of control" than those under 30 years old.
- In relation to differences between professions, there were differences between "empathy and congruence" and "fear of dependence, physical degradation and loss of control" before the intervention, but these disappeared after the training.

2. The intervention that addressed personal well-being and helping relationship skills did reduce burnout:
   - Analysis of the quantitative data showed a significant correlation between burnout and personal well-being and between burnout and perception of helping relationship skills, showing that personal well-being and competence in helping relationship skills has an influence on burnout.
   - Although HCW's levels of burnout were not high before the intervention, there were significant reductions in all three dimensions of burnout after the intervention.
   - Analysis of burnout items specifically related to end of life care showed that these levels were higher than items related to general burnout and that before the intervention these levels were above the cut-off point for HCWs working in other units but were reduced to below the cut-off point after the training.

3. An increase in sense of personal well-being and a reduction in death anxiety will improve perception of competency in helping relationship skills
   - Analysis of the quantitative data showed a significant correlation between sense of personal well-being and death anxiety with perception of competency in helping relationship skills showing that the former influence the latter.

- Analysis of the quantitative data also showed an increase in personal well-being, a reduction in death anxiety reduction and an increase in the perception of helping relationship skills.

Analysis of the qualitative data showed that these supported the quantitative results, with the exception of burnout, where it seemed that HCWs suffered more from burnout than implied by the results of the quantitative data.

6. DISCUSSION

The discussion of this thesis is organised in several parts. It will briefly discuss whether or not the hypotheses were supported or refuted. Following this introduction, the next sections will analyse the results of the main themes blending the qualitative with the quantitative data. The results will also be critically analysed and compared to other studies. The discussion will then return to the theoretical framework which was discussed in the Literature Review looking at the framework for burnout in end of life care and presented in fig 5 (page 61) analyse this in light of the results and present a final updated framework which will help understand the contribution of these findings for theory. The final sections will provide a critical account of the strengths and weaknesses of the research.

6.1 HYPOTHESES

The central question of this research is “Can an intervention addressing a combination of personal well-being related to existential issues, and practical helping relationship skills reduce burnout in health care workers who care for patients with a terminal condition and increase their self-perceived capacity to engage in an effective helping relationship”? This is an area with little research, and to the knowledge of the author, no research has been performed in this area to date in Portugal (Pereira, et al., 2012). The main hypothesis to this central question is that as a result of a reduction in death-related fears, an increase in existential well-being and an increase in the perception of their own competence in their helping relationship skills, HCWs would experience a significant reduction in their levels of burnout and an increase in their capacity to engage in an effective helping relationship. In general, although the results appear to confirm the hypothesis that an intervention that includes focusing on existential personal well-being and skills to improve their helping relationship with the patient and family does in fact reduce burnout and increase HCWs’ capacity to engage in an effective helping relationship, there were some areas which showed limited or no improvement. These will be addressed in the next sections. This main question was broken down into three questions and hypotheses:

The first hypothesis:

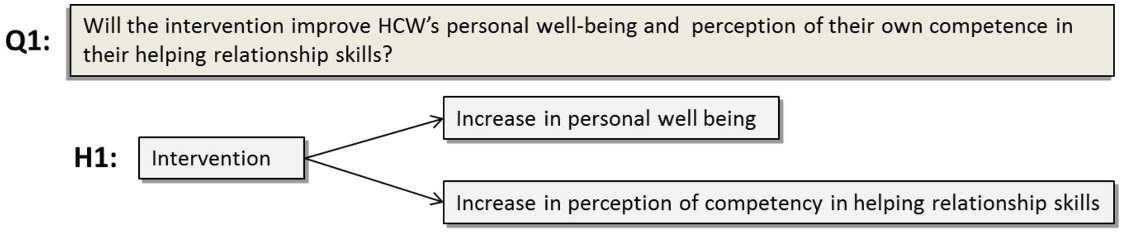


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FIGURE 46 - HYPOTHESIS 1

The intervention aimed to increase the capacity of the HCW to engage in an effective helping relationship without resorting to avoidance mechanisms. The aim was to achieve this by enabling HCWs to reflect on their personal fears related to death and dying, in developing close personal relationships and on living a meaningful life, as these are issues that may cause anxiety in patients with a terminal condition, and subsequently in the HCWs who care for them. This would be followed by increasing the confidence of HCWs in their capabilities in helping relationship skills by increasing their knowledge both theoretically and with practical exercises on how to provide emotional and spiritual care and on how to improve the quality of their presence and listening skills.

The quantitative results showed there were significant positive changes from T1 to T2 in all factors (Figure 12), except for one: "Self criticism regarding no time for family and close relationships" and this was only seen in the intervention group and no changes were seen in the control group (see Figures 17 and 18 of results section). This would seem to confirm the first hypothesis H1: The intervention appears to be an effective instrument to improve levels of HCWs personal well-being and perception of their competence in helping relationship skills.

Some discrepancy between qualitative and quantitative results, however, was found. Although the quantitative results showed positive changes, the qualitative results show that caution is needed when interpreting the results, as some HCWs perceived no change in personal well being. Possible reasons for this will be discussed below.

The second hypothesis:

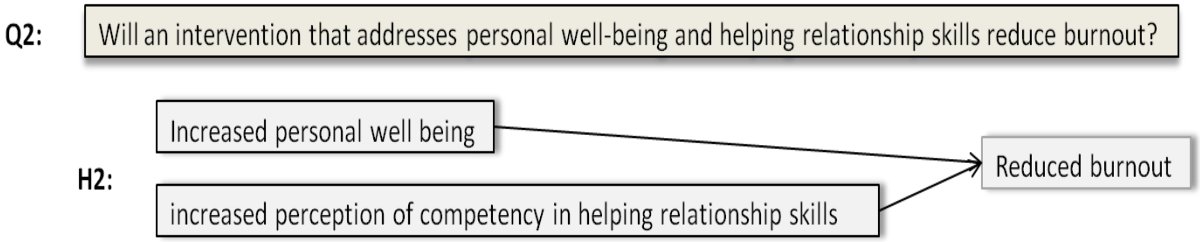
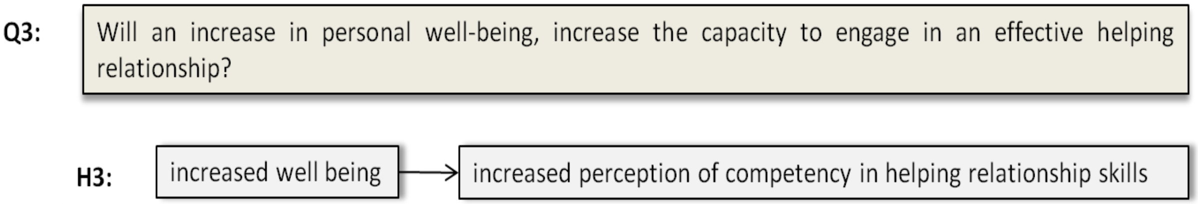


FIGURE 47 - HYPOTHESIS 2

The results show that there also seems to be a clear relationship between the negative factors of the helping relationship and the negative factors of burnout and between the positive factors of the helping relationship and the positive factor of burnout (Section 4.2.6). This would seem to confirm that increasing the skills in the helping relationship influences burnout. It would also seem that there is a relationship between the negative factors of personal well-being and the negative factors of burnout and between the positive factors of personal well-being and the positive factor of burnout. This again would seem to confirm that feelings of personal well-being also have an influence on resistance to suffering from burnout. These results confirm the second hypothesis H2: as a result of an improvement in personal well-being and perception of their own competencies of helping relationship skills, there appears to be a reduction in levels of burnout.

However, once again, the qualitative results show that caution is needed when interpreting the results. For example, some HCWs showed signs of depersonalization caused mainly by work overload (see table 42). This would also explain the lack of change in the factor “Self criticism regarding no time for family and close relationships”

The third hypothesis:



Q3: Will an increase in personal well-being, increase the capacity to engage in an effective helping relationship?

H3: increased well being → increased perception of competency in helping relationship skills

FIGURE 48 - HYPOTHESIS 3

The results again seem to show that there is a relationship between the positive factors of personal well-being and the positive factors of the helping relationship and between the negative factors of personal well-being and the negative factors of the negative factors of the helping relationship (Section 4.2.6). This would appear to show that reducing the fears related to death and dying and increasing the existential well-being can in fact contribute towards a genuine and effective relationship between the HCW and patient/family. These results confirm H3: as a result of an improvement in personal well-being, there seems to be a self reported improvement in the helping relationship.

The results of these 3 hypotheses appear to support the view that education that only considers the development of a more positive helping relationship and ways to combat burnout in the working environment may not be sufficient for HCWs who care for patients with a terminal condition. There is a need to also consider their personal well-being and internal congruence, which encompasses feelings of death anxiety, as this too, plays an important role in their ability to avoid burnout and engage with the patient and their family.

6.2 DISCUSSION OF MAIN THEMES

Death Anxiety, burnout, and how this affects patient care

Death anxiety can be manifested in different forms as shown in section 2.3.1. The results of the pre-intervention qualitative analysis showed that issues related to dealing with suffering were common in all HCWs, though some were more pronounced in HCWs out of palliative care. These were difficulties such as accepting there is no cure (Whippen D.A., Canellos, G.P., 1991; Fillion & Saint-Laurent, 2003; Williams, et al., 2005; Currow & Hegarty, 2006) or how to give hope to patients who relapse, and managing physical pain when doctors will not give adequate medication, for fear of accelerating their death (Florio, et al., 1998; Fillion & Saint-Laurent, 2003). Other common difficulties were struggling with the feeling that calling in palliative care would be accepting they were going to die and this made them feel they were giving up on them (Ruszniewski & Zivkovic, 1999). However, other HCWs also mentioned the emotional dilemma of continuing treatment so as not to “give up”, but then watching the patient suffer the consequences of active but futile treatment. Similar to the findings of Payne (1998), death in young people was also very difficult for all HCWs.

These difficulties can result in avoidance mechanisms, such as the conspiracy of silence (Back et.al., 2005; Friedrichsen & Milberg, 2006) and results showed that this was common to both populations because even though those in palliative care had received training and knew all the theory, often, the uneasiness they felt in certain situations made them resort to these avoidance mechanisms despite their training.

This can occur, because death anxiety can interfere with the HCW’s internal congruence, which in turn can reflect on their relationship with the patient. This has been approached several times in the literature. Lowry (1997) argued that doctors’ own fear of dying may compromise the palliative care their patients receive; Balfour Mount (as cited by Lowry 1997) has also maintained that people who provide health care may themselves be afraid of death, and this can undermine their ability to minister to the needs of terminally ill patients (Lowry, 1997). Their own fears of the process preceding death, such as dependence on others, physical degradation, and of loss of control, that they are constantly reminded of when caring for patients in this situation may also affect their internal congruence (Lawton, 2000; Abdel-Khalek, 2002; Mercadier, 2002; Connelly, 2009) More recent studies also support this view: Chow, A. (2011) mentions the studies of Kirchberg and Neimeyer (1991, 1998) where they describe that death anxiety is a major source of stress for counsellors dealing with EOL issues. Counsellors who perceived their personal mortality in fatalistic terms and avoided reminders of death, had higher levels of distress when seeing clients with EOL issues, and they were also found to respond in non-empathic ways. This view has also been supported by a recent review of the literature (Peters, et al., 2013).

Other studies have provided a more graphic illustration of how coping with suffering can be difficult. HCWs in end of life care, must cope with strong smells, sounds and facial expressions that communicate pain, and unsightly wounds, and this may also remind them of their own mortality and cause uneasiness (Payne, 1998; Mercadier, 2002). These findings are supported by this study, in which over half of the participants had positive scores on the fear of dependence and physical degradation factor and even after the intervention, the mean score was still just below the cut-off point. Furthermore, the qualitative results also confirmed these results. At the beginning of the intervention, when HCWs were asked to list their difficulties, fears of dependence and physical degradation were hardly mentioned. However, when a brainstorming around the word “death” was performed, many comments were made regarding emotional and spiritual matters, but the details of physical degradation were hardly mentioned as they declared they were “used to it”. However, when focusing deeper into this issue, some difficulties began to emerge as described in the qualitative results (section on internal incongruence). This shows that this is a difficulty within themselves that HCWs are not fully conscious of, but which may affect the helping relationship and contribute towards burnout, as shown in the results section where there are positive correlations between fear of dependence and physical degradation and avoidance mechanisms + emotional exhaustion).

These findings support the need to address these issues in the preparation of HCWs who care for the dying and this may be achieved through personal development to improve their personal well-being and to help them cope better with death anxiety. By helping HCWs to accept that death is not a failure of medicine and by helping them cope with their own emotional difficulties, HCWs can learn to stay present with the patient in spite of feeling helpless. Personal development to address these issues may have the potential to allow them to shift to the concept that after doing all that needs and can to be done to ensure comfort, just being with the patient with a different quality of presence is extremely important to help the patient die ‘healed’, as discussed by Twycross, (2005).

In order to understand whether there was a change in their quality of presence and helping relationships skills, the qualitative results seem to confirm that an improvement may have occurred, showing that empathy and congruence improved. This can be considered directly opposed to avoidance mechanisms which changed considerably with the intervention and the qualitative results (see section 5.2.3 – spiritual support) showed that HCWs mentioned “empathy and listening skills” and “congruent/ no defences” as what changed the most in their relationship with the patient. During the intervention, the HCWs were able to experience how it felt to “remove their mask” and be themselves without fear of being judged, and in the qualitative feedback, we can see how this helped them understand how important it could be for the patient to also feel free to remove their mask. These are the benefits of Person Centred group therapy (Rogers, 1973). The increase in empathy and congruence also helped the HCW to feel more fulfilled at work and this was reflected in the quantitative results of burnout. Furthermore, considering their current perception of their performance before the training, (fig. 16 section 4.2.2) the difference in empathy/congruence is even more marked, which means that the intervention made them aware of certain aspects of empathy and listening skills that they were not aware of before.

Results in empathy and congruence between HCWs in and out of palliative care are different (fig. 22 and 23, section 4.2.3). While both groups appeared to feel that their empathy and congruence had significantly improved after the course, this was felt to be more evident among HCWs working outside of palliative care than those working in palliative care. Given that HCWs in palliative care are assumed to have more training in communication skills, these results are not surprising. HCWs over

30 years old scored higher in empathy and congruence both before and after the intervention, but those over 30 years old made more progress with the intervention than the younger HCWs, perhaps because more life experience should increase one's capacity to empathize (fig 26, section 4.2.3). This was suggested by Rogers (1951) who argued that people can increase their capacity to empathize in several ways, for example by having a broad experiential knowledge of the human being or by learning more about the experience of other individuals through reading, studying or simply through the process of living. This can be illustrated by the nursing aides who scored the lowest before the training, but were the ones to make the most progress after the course, and most of them were over 30 years old.

Other causes for discomfort which may contribute towards burnout in HCWs are the stress caused by work overload (Fillion & Saint-Laurent, 2003; Pereira, 2011) and consequent lack of time to spend with family and doing meaningful activities in their lives (Jones, 2009) and finally, the avoidance mechanisms that HCWs use to cope with their fears and efforts to try to avoid suffering (Lowry, 1997), which may lead to burnout (Jackson, et al., 2008). These difficulties were reflected in the qualitative results, as were others related to work overload, such as not having time to grieve over patients' deaths. This was felt by HCWs from all units and was also found in several other studies, (Fawzy, et al., 1991; Florio, et al., 1998; Vachon, 2000; Fillion & Saint-Laurent, 2003; Bressi, et al., 2008).

However, it may seem that these difficulties do not affect levels of burnout. Similar to other studies which show that levels of burnout in HCWs who care for the dying in Portugal are low (McIntyre, 1994; Soares, 2010; Pereira, et al., 2012), levels of emotional exhaustion and depersonalization in the quantitative part of this study were also below the cut-off point (see fig. 12). However, results from the qualitative results suggest that these HCWs are under considerable stress (see section 5.2.6 – burnout) as their comments show signs of both emotional exhaustion and depersonalization, with a negative effect on work efficiency. During an initial survey performed before this study (appendix 11), it became apparent that reasons for burnout in HCWs who care for the dying may be different from HCWs in general and for this reason a questionnaire was designed specifically to measure burnout in this population (Gouveia e Melo & Oliver, 2012).

In this study, the mean scores for burnout — in particular, emotional exhaustion and depersonalization — show that before the course, HCWs did not have high levels of burnout, but improvements after the course were still significant. Comparison of EG1 (HCWs who cared for patients with a terminal condition in other units and who participated in the intervention) with the control group shows a significant positive change in all three dimensions of burnout but no significant difference was found within the control group. However despite these results, the large majority of HCWs still considered themselves professionally fulfilled. These results seem to imply that professional fulfilment may not be affected by emotional exhaustion. However the qualitative data also shows that despite these quantitative results, the difficult working conditions still lead at times to levels of exhaustion that can, in some cases, result in negative behaviours. Furthermore, the pre-intervention qualitative results showed that none of the units had any kind of supervision or emotional support for their personnel, which HCWs mentioned they needed. These findings are in line with the mediation model of burnout (fig 2 and 5) (Leiter & Maslach, 2005), which shows work overload as a cause for burnout, and with another large Portuguese study, which showed that HCWs in palliative care units are at low risk for burnout, but despite this, there are significant risk factors that may affect their performance, and contribute towards exhaustion, such as work overload, disorganisation and difficult relationships (Pereira, et al., 2012).

Considering the levels of emotional exhaustion and depersonalization described by the participants and in an attempt to understand whether these levels were really low, or whether this was due to the questionnaire not being adapted to this population and therefore not measuring burnout correctly, a separate analysis was performed, distinguishing the questions devised by the author specifically for HCWs who care for patients with a terminal condition and the other questions for Human Services in general. The results showed that the mean result for emotional exhaustion for questions designed specifically for HCWs who care for patients with a terminal condition was higher than for the other questions (see Table 22 and Table 23 section 4.2.4). This would seem to confirm the initial survey, which showed that HCWs who care for patients with a terminal condition have specific causes for burnout (Gouveia e Melo & Oliver, 2012) and this has also been shown in the literature review (Hennezel, 1998; Payne, 2001; Vachon, 2000; Jünger, et al., 2007; Fillion, et al., 2007).

However, when separating HCWs in and out of palliative care units (Table 25, section 4.2.4), the mean scores and percentage of HCWs above the cut-off point show that the results for depersonalization and professional fulfilment were basically the same, but when emotional exhaustion was considered, HCWs out of palliative care units were above the cut-off point and those in palliative care units were not. This would seem to show that emotional exhaustion is more accentuated in HCWs with no training in palliative care (Ramirez, et al., 1995; Pronost & Tap, 1996). However, the qualitative results show that not being able to spend quality time with patients due to work overload was particularly upsetting for HCWs in palliative care units, because they joined palliative care specifically to be able to provide a different type of care. In order to understand this, further analyses were performed.

To see if this could be supported by the questionnaire on burnout, the individual items were analyzed: (Table 26, section 4.2.4). These results help to explain the difference in quantitative and qualitative results. They show that HCWs working out of palliative care units and without the adequate palliative care training may experience more difficulties than their palliative care colleagues. HCWs in palliative care units have a greater awareness of their role and can see that "doing more" may not necessarily be looking at cure, but to provide comfort. (Yang, et al., 2011). These aims are part of the wider palliative care philosophy not to see death as a failure. Palliative care HCWs had received more training in communication, in teamwork, and in providing more quality of life to patients, and this may have made them feel more competent in their jobs, less helpless in the face of suffering, and less emotionally exhausted, as also found in a more recent study (Pereira, et al., 2012). The intervention seems to have helped the HCWs working in other units to develop some of the competencies and assurance that the trained palliative care workers had already acquired. On the other hand, the fact that HCWs in palliative care units feel they work too hard could be linked to what was found in the qualitative data: these HCWs chose to work in palliative care units in order to have more quality time to spend with their patients. However, with the lack of palliative care beds, and staff due to hospitals' financial restraints, the ratio HCWs/patients is far higher than supposed to be, and HCWs find themselves working at the same rhythm as in curative medicine. The quantitative questions confirm that the stress for HCWs in palliative care units is linked to work overload which affects their sense of competence in providing total care: if they had time to give quality emotional and spiritual care to patients, they would probably not feel so helpless when faced with their fragility.

In terms of age, studies have shown varying results. Studies from Italy and France (Quattrin, et al., 2006; Lissandre, et al., 2008) suggest that older HCWs who have been in the same service for long periods of time suffer from higher levels of burnout than younger HCWs. Studies by Maslach et al. (2001) and Vachon (1997) suggest the contrary: HCWs above 30-40years old have lower levels of burnout. Results from this research showed no significant difference between over and under 30 years old, but, the younger HCWs scored slightly higher in emotional exhaustion and depersonalization and slightly lower in professional fulfilment, both before and after the course.

Reasons for this difference may be linked to work priorities and distancing from work. Comments during the interventions for example showed that the stressors that lead young HCWs to burnout are not the same as the stressors for older HCWs. Younger HCWs complained more of lack of personnel which resulted in not being able to spend enough quality time with patients and they were still very much engaged in their work. This is also supported by a Spanish study that shows that older nurses provide less personalized care than younger nurses (Martínez Garcia, et al., 2009). The comments from older HCWs however, often revealed a desire to spend more time at home, enjoying family life and daily household affairs like cooking and gardening. Although no studies were found supporting these wishes of older nurses, the literature shows that there are other factors that may contribute towards older nurses' wish for retirement, such as the pace of technological change, stress at work and working in shifts (Andrews, et al., 2005; Department of Health, Melbourne, Victoria, 2010).

Added to this and in this study, HCWs under 30 had high scores related to frustration at not having enough quality time to spend with the patient, and for HCWs over 30, their frustration was more related to work overload.

Furthermore, looking at the mean score of nursing aides, and those of nurses and "other professionals", although there are no significant differences between the different professions, the nursing aides, who have the least education, scored the highest in emotional exhaustion. This supported the findings by Martínez Garcia, et al. (2009) who showed that lack of training is positively correlated with increased emotional exhaustion. In the intervention, the fact that the groups were mixed, helped to create a stronger group cohesion and understanding of colleagues within the team and also, to understand what good palliative care can do to improve the quality of life of the patient, which would reduce their sense of helplessness and increase their sense of professional fulfilment. Supervision with a mixture of different disciplines has also been advocated by Jones (2008), who claims this can decrease the sense of professional isolation and can promote learning and knowledge from the experience of others.

Analysis of the qualitative data also showed that although emotional exhaustion and depersonalization reduced significantly, they still continue to be present, mainly due to work overload (see section 5.2.6). Emotional exhaustion was expressed through physical tiredness, less attention to detail, feelings of saturation, demotivation and mistakes at work. Attitudes of depersonalization were expressed as working in a mechanical way and answering patients in a hurried and automatic manner, not making an effort to understand them. The qualitative results by Pereira (2012) also showed signs of saturation by Portuguese HCWs in palliative care units and lack of staff was a common issue in the study by Jünger (2007).

The other relevant form of death anxiety is the HCW's own fear of death, physical degradation and loss of control. Fear of dependence, physical degradation and loss of control is seen as the highest of the negative factors.

To understand this, the scores of individual items related to death anxiety were analysed and showed that the item with the highest score in HCWs in palliative care units was related to the need to talk to people close to them if they were to die, and in HCWs who worked in other units, the item with the highest score was related to the fear of suffering, where the desire to die a quick death was more important than having the time to prepare one's death. HCWs in palliative care units are more sensitive to the importance of existential issues and are more aware of the fact that physical pain can be controlled, and the time before death is valuable, whereas with HCWs in other units, physical pain, degradation and not being in control may cause more anxiety.

Training in palliative care makes HCWs well aware of the fact that the time between the beginning of a terminal condition and death is important in a person's life, and is a time when important changes can happen. This is also symptomatic of what often happens when HCWs in other units (often doctors) are faced with a patient they cannot cure: they cease to invest in them, which, although not intentional, may contribute towards making them feel they are no longer of value. However, apart from these items, in general, the fears between HCWs in and out of palliative care are not very different.

To further understand how death anxiety may contribute towards burnout, the correlations of burnout with other factors of this study were analysed and positive correlations were found between burnout and fear of dependence and physical degradation, no time for family and meaningful activities and avoidance mechanisms. These factors are mainly from the questionnaire on personal well-being and one factor, (avoidance mechanisms), is from the Barrett-Lennard Helping Relationship Inventory. Similar results were also found in a Chinese study (Chow, 2011), where a reduction in death anxiety was achieved through several exercises of existential nature, and this was positively correlated with increased comfort and competence in working with dying and bereaved persons.

Age seems to play an important role here. Results show that HCWs under 30 scored higher than HCWs over 30, and were only just able to reduce their fear of dependence, physical degradation and loss of control to below the cut-off point after the training and in terms of percentage, HCWs over 30 reduced their fears more than those under 30 (fig. 30 of section 4.2.3). This may be because the older group had greater self-confidence in the face of adversity and illness (fig 28 section 4.2.3), which is the factor opposing 'fear of dependence, physical degradation and loss of control) and because their idea of what is physically tolerable may have changed with age and personal and professional experience of illness. Contrary to this, a younger person may be more attached to physical beauty and feel more threatened by suffering and physical degradation and therefore consider living with a serious physical infirmity unbearable, thinking they would prefer to die. However, as they get older, and find themselves living with less and less health, but still being able to enjoy other things in life, their views may change. Other studies have shown that young HCWs prefer to care for younger patients because older people disturb them due to their fear and denial of their own aging, and this can affect their work (Bennett, 1976). Furthermore, of the professional categories studied, nursing aides showed the most fear, followed by nurses (figs 32 and 33, section 4.2.3), but the nursing aides were the category who made the most progress and as most of the nursing aides were over 30, compared to only a third of the nurses, this reinforces the importance of age for this factor. Caution is needed in this interpretation however, because these HCWs were also the category with no formal training, which may have been one of the reasons more progress was made.

Looking at the comments from HCWs in the thematic analysis many quotes were found regarding the awareness for more quality in their lives, such as better personal relationships, more time to enjoy life, the need for more training of this type, which allows for increased self-awareness and knowledge, but there was a paucity of comments regarding their feelings if they were to become ill, dependant and watch their slow physical degradation. A possible reason for this is that although the subject was present in the intervention, it did not occupy a large part of the course curriculum. However, studies by Rosenfeld, et al. (2000) on the reasons patients may seek hastened death, show that the link between physical pain and desire to die is not all that simple, and factors such as depression, lack of social support, and feeling a burden to others also play a very important role. If these aspects are cared for, as they are more likely to be so in a palliative care unit, the request for euthanasia is very rare. For this reason, more time was given during the course for the HCWs to reflect on living with meaningfulness, their personal relationships, their personal resources, and caring for themselves, presuming that as a consequence, the fears of dependence, physical degradation and loss of control would decrease. Nonetheless, the fact that this fear still remained relatively high shows that this aspect of the course needs to be revised, giving more direct attention to this physical aspect of HCWs' fears. However, as mentioned in the methodology, some caution is needed when interpreting the results of this factor, as it was the only factor that did not show satisfactory results in the baseline studies.There should have been no significant difference between the control group and the experimental group at T1, but results were higher for the control group in this particular factor. The reasons for this are not clear.

Having looked at fear of dependence and physical degradation as a cause for burnout, there is a need to also consider avoidance mechanisms, which, as a consequence of death anxiety and lack of communication skills, can also contribute towards exacerbating burnout. Bernard and Creux (2003) discuss the use of defence mechanisms (described in this study as "avoidance mechanisms") to cope with the constant confrontation with suffering and death. They suggest that the continuous effort to relieve suffering when this may not always be achievable can lead to emotional exhaustion. Defence mechanisms adopted by HCWs — such as avoidance of the truth, trivialization, or derision — can have negative effects on the patients, who may not feel comfortable talking to HCWs about their troubles and thus become isolated in their world of illness (Meier, et al., 2001; Bernard & Creux, 2003; Williams, et al., 2005; Currow & Hegarty, 2006).

In this study, avoidance mechanisms as described by Bernard & Creux (2003) and Hennezel (1998) were shown clearly through the qualitative analysis (see section 5.2.1 – avoidance mechanisms). Some of the HCWs' comments illustrate that one of the main reasons why HCWs may end up avoiding the patient is that they find it difficult to cope with the patient's fears and anxieties when they do not feel there is something they can do about it, for example when they avoid looking at them in the eyes when they don't want to talk. They also mentioned that as a consequence of this, they risk being perceived as cold. The comments also illustrate how avoiding the patient in order to avoid their suffering, does not have the desired effect, because they feel they haven't helped the patient, and this may make them feel guilty and may reduce their sense of professional fulfilment. This has been confirmed by a study showing that when patients perceive HCWs to be withdrawn, they tend to feel abandoned and without backup (Larsson, et al., 2011).

This study shows the importance of including HCWs' personal well-being in the burnout equation. The results indicate a strong correlation between emotional exhaustion and no time for family and meaningful activities; they suggest that emotional exhaustion at work can be exacerbated when HCWs feel they are not dedicating enough time to their families and to (non-work-related) activities that give meaning to their lives. Only this factor showed no significant change after the course in the general results. This may reflect the fact that looking at and making significant changes to one's personal relationships and lifestyle is important but may not be achieved in a six-day course, reinforcing the need for continuous emotional support for HCWs. A similar study by Chow (2011, 2013) using the ENABLE program, also failed to achieve a significant change in the area of regrets in relation to cultivating relationships within the short period of the time of their intervention. However, once again, a separate analysis of the results of HCWs caring for patients with a terminal condition in and out of palliative care units shows that before the intervention, HCWs in palliative care units were less critical of themselves regarding time spent with loved ones than HCWs in other units, but after the intervention they were more critical in comparison to HCWs in other units. A possible explanation for this is that HCWs trained in palliative care may have already made an effort to be closer to their loved ones and the training only heightened their awareness of the limitations imposed by long working hours and staff shortages, whereas HCWs with no palliative care training may have been making the effort for the first time, with significant results. This tendency for palliative care personnel to become more aware of the importance of living life to the full has been highlighted by Hennezel (1998), who claims that "the dying teach us to live".

It is also interesting to note in the questionnaire on well-being, that all the changes which occurred before and after the intervention were highly significant, except for "close relationships and personal well-being", which was significant, but at a lower p-value. However, looking at their current perception of how they thought they were before the training, compared to results after the intervention, the difference is very significant. In other words, did their relationships and personal well-being improve a lot, or did they just realize how much could and needed to be done to improve things at home and that their situation was not as good as they had originally thought? Considering that there was no significant change in the factor "Self-criticism regarding time for family, friends and meaningful activities", before and after the intervention, one is led to believe the latter. This is in agreement with the findings of Chow (2013), as discussed above and with the qualitative feedback, (section 5.2.1 – team and workpplace), where work overload was mentioned in written answers and verbally during the trainings as a cause of stress. When talking about the need to care for oneself, and what they could do to improve this, lack of time due to how much overtime they did, was mentioned very often, and this was an impediment to spending quality time with the family (Pereira, et al., 2012). However, the qualitative feedback shows that HCWs were able to make significant personal changes, such as more self-awareness, confidence and assertiveness and that this had allowed them to change at work by becoming more genuine and less defensive with the patient.

The course of this discussion will show how the intervention, consisting of personal development associated with a better understanding of how to provide psychological and spiritual support to patients with a terminal condition, can help HCWs find meaning in their work despite difficult working conditions.

The Intervention

The following sections will focus on the intervention itself, starting by the structure and teaching methods and followed by a critical review and improvements to be made.

The structure and teaching methods

As mentioned in the literature review and explained in the methodology, in order to emotionally prepare HCWs to provide quality care for patients with a terminal condition, with less risk of burnout, there is a need for a specific type of intervention. Before addressing issues related to helping relationship skills such as emotional and spiritual support, the intervention should address the death anxiety experienced by these HCWs, which may compromise their capacity to provide an effective helping relationship. In order to effectively address the different forms of death anxiety, it would be advisable to give individual attention to each HCW and therefore, the interventions should be carried out in small groups. The constitution of the groups may play a part, in that groups with different professions seem to have a greater effect on the participants. Finally, teaching methods may make a difference in how the participants assimilate information. It would seem that interventions mentioned in the literature review have addressed some of these issues, but not all simultaneously.

A recent intervention called ENABLE (Chow, 2011) was designed to address existential issues related to death anxiety, and also had a component of helping relationship skills, but the groups had 23 participants in each which may have been a reason why it did not produce all the desired results, namely in terms of reflection of past, present and future regrets. Other interventions have also associated contemplative practices with other practices that foster self development together with qualitative time where participants could express and deal with their own grief in a supportive atmosphere without being judged, such as the course provided by Rushton et al (2009), Fillion et al (2009) and Todaro-Francheschi (2011). These interventions seem to have provided the participants with the contents needed to improve the quality of care to dying patients. However, they also had large numbers of participants in each intervention and may not have allowed for individualised attention to address the different aspects of death anxiety of each participant and it does not seem that the interventions were designed to first address death anxiety before addressing patient care.

With consideration of the methodology and group constitution of the intervention, analysis of the pre-intervention qualitative data showed that some of the HCWs' difficulties consisted of showing their vulnerabilities and feelings within the group. For this reason, as required in support groups, an environment was created where there was liberty to share feelings, without the fear of being judged, but this was more challenging in this case, because of the mixture of different professions. However as suggested by Jones (2008) and Medland (2004), and confirmed by the qualitative results of my study, being part of a multidisciplinary group was appreciated for various reasons such as getting to know each other as a team, hearing feedback about themselves from their colleagues, learning from the experience of other colleagues and knowing that they are not alone in their difficulties.

Finally, no interventions were found that specifically mentioned the type of teaching methods, however, the qualitative results seemed to show the benefits of methods which allowed them first to reflect and experience situations, voice their opinions and only after, when they had reached their own conclusions, have this complemented with theoretical information by the facilitator. It is possible that this method was appreciated because participants were encouraged to think and come to their own conclusions before considering the opinions of other authors.

My intervention differed to other interventions described in the literature, mainly due to the combination of personal development to emotionally prepare the HCWs to cope with death and suffering without resorting to avoidance mechanisms, followed by a second module of helping relationship skills and due the the limited amount of participants in each group which allowed for personalised attention.

Critical review of the intervention

The following section will analyse the strengths and weaknesses of this intervention for HCWs who care for patients with a terminal condition. The section will begin with the strengths, however these need to be regarded taking into consideration the weaknesses described in the methods, and summarized in the limitations section below.

As shown in the qualitative results, not knowing what to say when in the presence of suffering was an issue for HCWs. The intervention appeared to help them to understand the value of being present and listening and this seemed to reduce their feelings of helplessness even if they did not have solutions to give. Consequently this may also have decreased their need for avoidance mechanisms. By sharing and reflecting with other members of the group on their difficulties in coping with and accepting difficult and unpleasant family members, the intervention also seemed to help them become more tolerant and understanding with these families, which is an important part of the concept of palliative care.

It appears that the intervention was beneficial in helping HCWs cope with their own death anxiety by allowing space for each participant to work on these issues through individual exercises and then share them within the group, unless they wished not to and this may have contributed towards increasing their internal congruence. Although the intervention did not allow for "magic" changes to occur in six days, it was a starting point for HCWs to become aware of changes in their life and practice that needed to occur, and to understand what causes them anxiety when in the presence of suffering (Hennezel & Leloup, 1997; Hennezel, 1998). This awareness may make it easier for them to temporarily put their issues aside, in order to be fully present with the patient. If they are not aware of their internal feelings, and able to accept them, it is unlikely they will be able to maintain themselves centred on the patient (Rogers, 1951). This intervention may have helped them to understand that the solution is not to create distance between themselves and the patient, but between themselves and their feelings (Hennezel, 1998). This means that it is as if a conscious part of oneself has distanced itself from the body and emotions in order to see the big picture more objectively and thereby keep them feeling more grounded and in control as illustrated in fig. 49 as the HCW observing the ego:

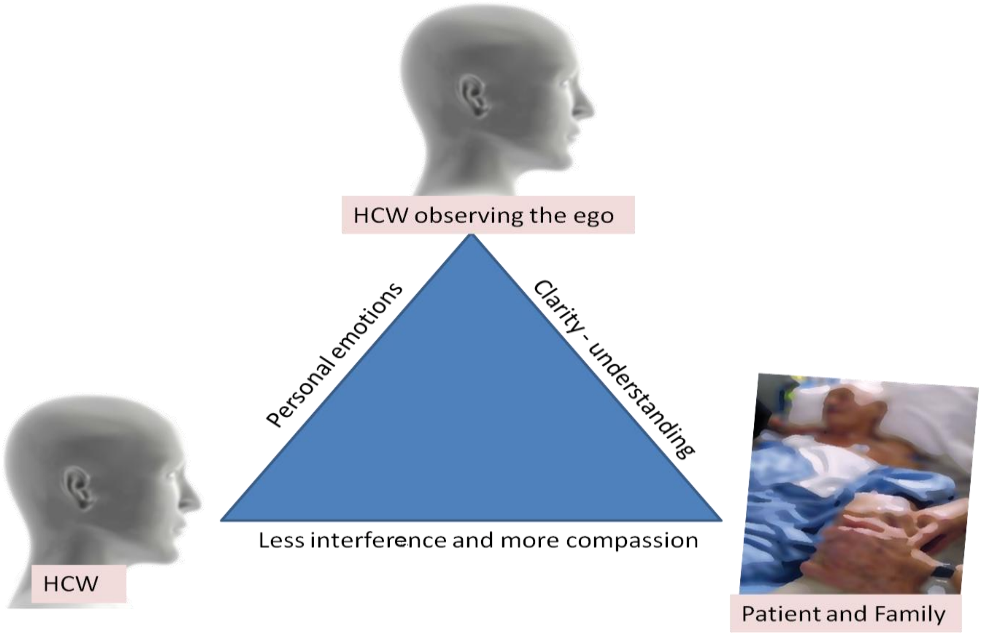


FIGURE 49 - OBSERVING THE EGO

As described by Junger (2007) and shown in the qualitative results (section 5.2.1 team and workplace), difficulties experienced with their fellow colleagues within the team was an issue. The intervention aimed to provide a common philosophy for the team and this was strengthened by the fact that the group was multidisciplinary, from nursing aides up to doctors and clinical directors. It not only gave an opportunity for doctors and head nurses to get to know their team better, but often allowed personnel to see the more human and vulnerable side of their superiors and this did have a positive effect on the team. On several occasions, existing conflicts between team members were also resolved. However, as the months passed with no more opportunities for team support, conflicts within the team did return. Not surprisingly, the need for more training and group encounters were the two greatest needs mentioned in the qualitative results (section 5.2.6).

Finally, the institution and health care system can also prove to be a source of difficulty for the HCW: lack of cooperation between the referral and palliative care team (Ruszniewski & Zivkovic, 1999), and lack of awareness of what palliative care is on behalf of the society and government (APEME, 2008; Lynch, et al., 2010) may have consequences for the HCWs at various levels. Patients may not request palliative care because they are not aware of the benefits, and as funding is not abundant, palliative care units will not be a priority, resulting in a lack of beds in the health care system and a lack of funding for specialist training (Unidade de Missão para os Cuidados Continuados Integrados, 2010). This could increase the stress for HCWs who need to care for patients with a terminal condition all the same, but without the right conditions (Pereira, 2011). This problem was not addressed specifically in the intervention, but the benefits of palliative care were always present during the intervention, which may have been important for HCWs who did not work in palliative care units, to obtain a different perspective. This intervention continues to be given to hospital teams, both palliative and non-palliative, although it is mainly requested by teams without palliative care. The intervention is therefore one of the many ways to contribute towards promoting palliative care in Portugal.

Although feedback from HCWs was very positive, there was also some negative feedback regarding the intervention. Of the 29 groups trained, one did not go well, where there was already a lot of mistrust within the group before the intervention, and the facilitators were unable to create a therapeutic atmosphere. Consequently there was little sharing and this made the whole intervention less effective, as sharing experiences with one another is one of the main learning instruments. Confidentiality was also not maintained within this group. After the course, I did speak to the group as a whole, and to some members individually to minimize the negative effects, but this was not enough to repair the damage. On the whole it was a learning process in terms of group therapy. In Carl Rogers's Person Centred Therapy, congruence is an essential element for therapy to be successful, and if it is not present, the therapist needs to work on this to restore congruence, before continuing. This intervention is different from normal Person Centred group encounters, in the sense that there is a pre-planned structure. However, within this structure, the participants are given the freedom to explore their feelings and ideas. In this case however, having sensed the uneasiness within the group, which had also made me feel uncomfortable, I should have brought this to the awareness of the group, and discussed it, before continuing, even if it meant not getting through the course curriculum.

The qualitative results a few months after the course had terminated were useful to understand that there is a clear need for continuous emotional support. HCWs were tired from overwork which was constantly increasing, and were not feeling appreciated by their superiors. The general feeling was that although they had not forgotten what they learnt during the intervention, they were feeling weighed down from the stress and work overload and this was starting to have a negative effect on the team, with increasing conflicts, and some comments were found that indicated depersonalization (section 4.4.6). One nurse described the change over the months after the intervention as “a bright flame that was slowly dying”. As Diane Meier wrote in an article with Larry Beresford on preventing burnout, (Meier & Beresford, 2006), “if the palliative care program is simultaneously struggling with inadequate staffing, rapid growth in caseload and demand for services, lack of institutional support, or misconceptions from medical colleagues, the stage is set for professional burnout”. This continues to be the case in Portugal.

Improvements made to the Intervention

This intervention was given over the course of two and a half years, during which time it was possible to reflect on ways to improve the intervention. Together with feedback provided from the HCWs in the qualitative part of the research, four changes were made to future interventions. Firstly: if the course is given by two professionals, they should be given by psychotherapists trained in the same approach and for this, the Person Centred Approach (PCA) was adopted. Secondly: three days to cover the fears of life and death was considered insufficient in most courses, and therefore an extra day has been given and this has been greatly appreciated by subsequent interventions. Thirdly: to improve the quality of the helping relationship, HCWs are now given practical sessions in active listening according to the PCA. Although it is obviously not possible to learn the PCA in such a short period of time, it is enough for HCWs to understand the concept and also to understand that empathic answers can be much more helpful to patients than giving the patient solutions and suggestions with the intent of trying to “fix things”, that cannot really be fixed. This is uncomfortable for both the patient and the HCW. HCWs resort to the temptation to give advice because it gives them the false illusion that they are doing something to help. However, learning the PCA together with the personal development provided within the intervention provides the HCWs with the right attitudes and the basis of Rogerian counselling skills which will enable them to enter a helping relationship with the patient and family without these feelings of helplessness. Fourth: role-play is also provided to help the HCWs cope with the conspiracy of silence and to talk about difficult issues such as impending death or the communication of “bad news”.

To summarise the findings of this thesis, a synthesised model (fig. 50) is suggested that links the findings of the literature review and elaborates on the intervention itself, including the findings of this present research.

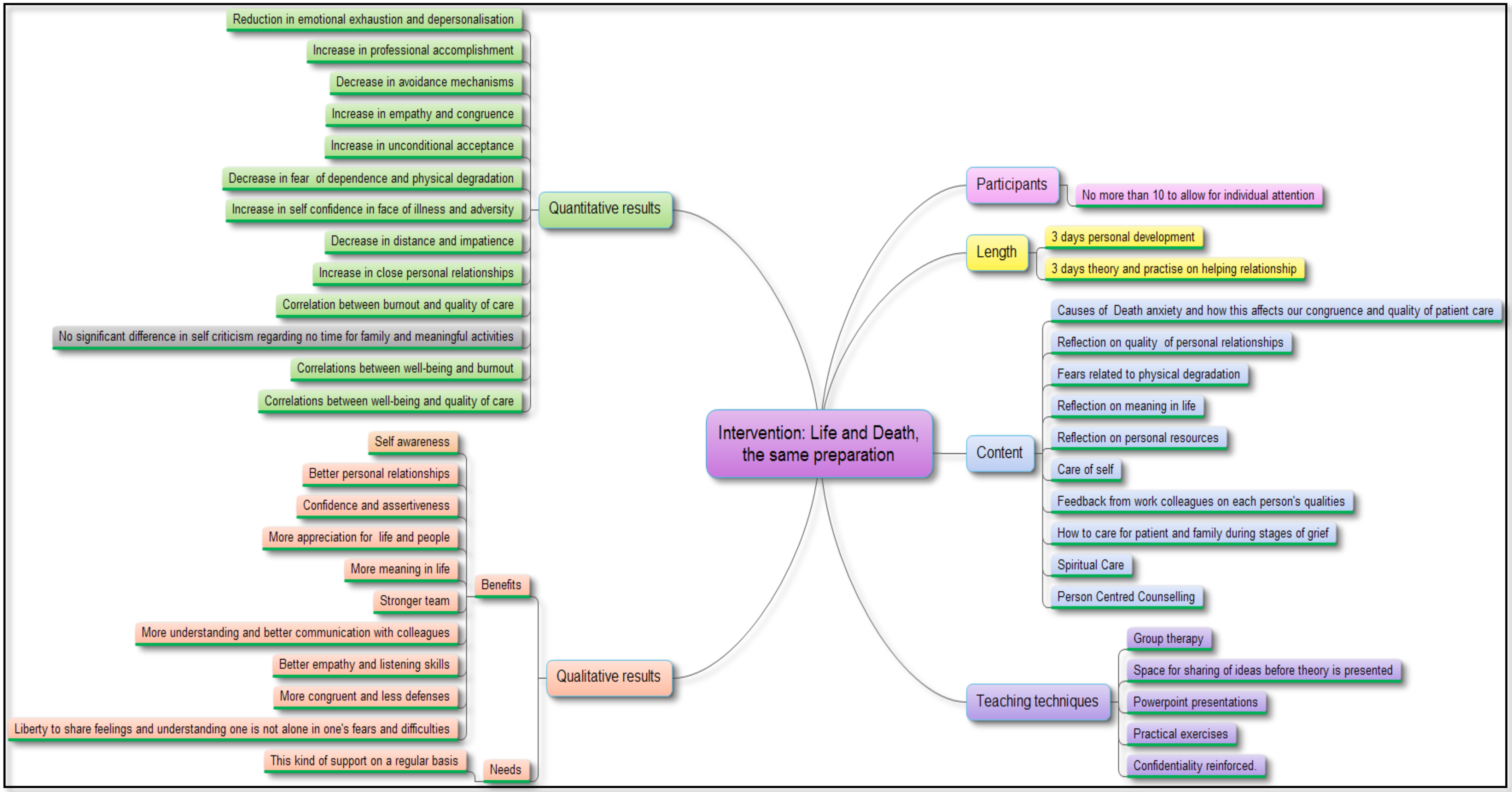


FIGURE 50 - SYNTHESIS OF INTERVENTION "LIFE AND DEATH, THE SAME PREPARATION"

6.3 IMPLICATIONS OF THE RESULTS FOR THEORY

Theories are integral to healthcare practice and can powerfully influence the understanding of health care and for this reason, it is practical and scientific to examine them (Alderson, 1998). Throughout this study, the author has sought to facilitate better understanding of burnout and death anxiety and how this may affect the HCWs, based on testing and redefining the theoretical constructs surrounding this topic area. This commenced with the literature review and at the end of the literature review the author proposed a new theoretical framework for burnout in HCWs who care for the dying (fig. 5). This framework included the mediation model of burnout by Leiter & Maslach (2005) which drew upon previous models of burnout (Karasek, 1979) (Maslach, et al., 1986) and added further research resulting in the 6 areas of worklife (Leiter & Maslach, 2005). It also included other variables such as life satisfaction (Demerouti, et al., 2000), existential well-being (Pines & Aronson, 1988), coping mechanisms (Fawzy, et al., 1991), the issue of compassion fatigue (Joinson, 1992) and the specific causes for burnout in end of life care found in the literature. To this, a further theoretical component was added, which was conceived by the author, consisting of self development to cope with death anxiety and a practical element comprising of helping relationship skills and continuous supervision/emotional support. The purpose of this addition was to facilitate greater explanation and understanding of the phenomenon of burnout in end of life care. This present section will comment on this framework in the light of the results of this study.

Both the literature review (section 2.2.1) and the present results show that death anxiety can interfere with the helping relationship and increase burnout. The quantitative results also established the positive effect of the intervention on these factors and highlighted the difficulty that HCWs have with the prospect of dependence and physical degradation (fig.12) suggesting that this is an aspect that requires more attention in the module of personal development. Although levels of ‘fear of dependence and physical degradation’ were relatively high in comparison to the other negative factors of the quantitative results, the sparcity of qualitative comments relating to this also helped to understand how this difficulty remains at a subconscious level, requiring more attention.

As also shown in the literature review (section 2.3.3), work overload in end of life care is an issue that has been widely mentioned, however the quantitative questionnaire did not contain many questions relating directly to work overload. In contrast, the qualitative comments, in agreement with the mediation model, showed that work overload continues to be the main factor contributing to emotional exhaustion and depersonalisation. Furthermore, the only factor that showed no improvement with the intervention was ‘self criticism regarding no time for family and meaningful activities’. As shown in the qualitative results, this factor is directly related to work overload and working overtime. It is suggested therefore, that a theoretical framework for burnout in end of life care should encompass the existential issues that contribute towards death anxiety as well as help HCWs cope with the effects of work overload that affect their levels of exhaustion and family life.

Figure 6 shows how the intervention is built around the theoretical framework shown in figure 5. Considering the results of this research, the aspect of the course that could be altered is the amount of emphasis placed on reflecting about their fear of dependence and physical degradation. However, work overload, which may in turn affect lack of quality time with family and doing meaningful activities, is not an aspect that is within the control of the participants to change. However, it is possible that regular group sessions of emotional support and supervision could help HCWs to learn to cope better with the stress and team conflicts caused by work overload and a greater awareness of how to improve the quality of the little time they have to spend with family may increase their personal well being.

Following is a new synthesised theoretical framework for burnout and its prevention (fig. 51), which also highlights the findings of this research. The left side of the diagram shows the theories featured in the literature review, but older theories that were absorbed by more recent theories were removed, making the diagram easier to read. The right side of the diagram shows the contribution of this study for the theory of burnout in end of life care and its prevention. The bubbles highlighted with a square show areas which the results of this study identified as areas that require special attention, namely group support to cope with work overload and conflicts within the team, and coming to terms with their own aging and prospect of physical dependence, degradation and death.

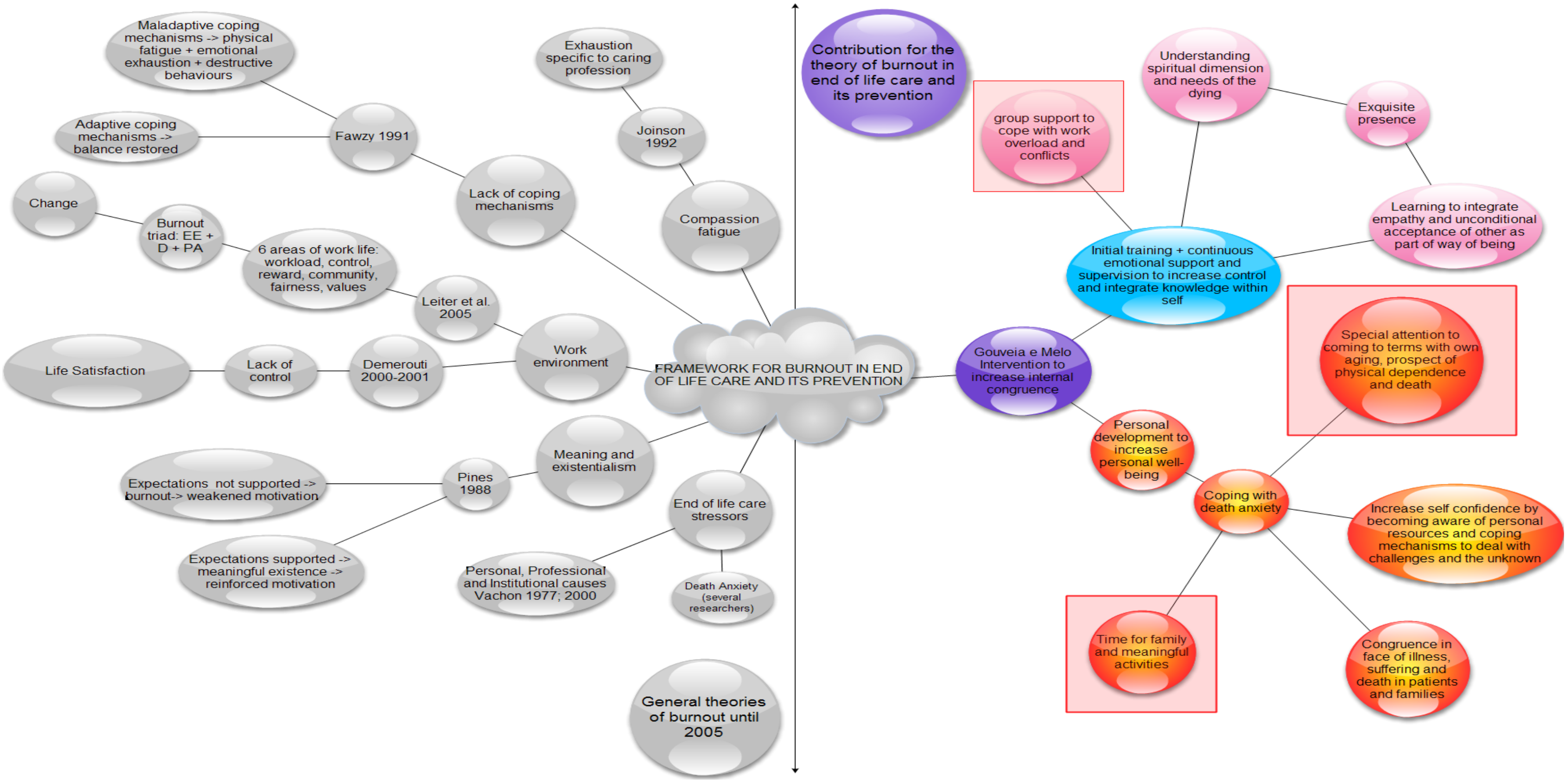


FIGURE 51 - FRAMEWORK FOR BURNOUT IN END OF LIFE CARE AND ITS PREVENTION

6.4 STRENGTHS

The compatibility of using mixed methods was considered to be a strength in this study. Following the reasons defended by Glasby & Beresford (2006) and Billings (2013) for using mixed methods, which were described in section 3.1.3, this section will use examples from the results to highlight some of the reasons why a triangulation of data (Robson, 2002) using quantitative questionnaires and qualitative data was indeed beneficial in obtaining information that would not have been possible with the use of only one method.

The quantitative data revealed that levels of burnout were not particularly high in this group of HCWs who care for the dying, but feedback from the qualitative data showed otherwise. This showed that work overload was a significant source of stress, however, as mentioned previously, few questions in the quantitative questionnaire were directly related to work overload. Information from the two sources therefore made it possible to obtain a more complete understanding of the sources of stress. Had only quantitative data been used, this information would not have come to light.

The same complementarity of using both qualitative and quanitative methods can be seen in the issue regarding fear of dependency and physical degradation. As explained in section 6.2, this was a difficulty that was rarely voluntarily articulated by HCWs during the intervention unless the subject was brought up, and there were few qualitative comments. However the quantitative data identified this problem well, as it was the negative factor with the highest scores, and after the intervention, the levels were only reduced to just below the cut-off point, implying that the intervention was not sufficient to effectively create substantial change. It is therefore an area that needs to be addressed in future interventions. This difficulty would not have been identified had the research only been qualitative.

Mixed methods were also useful as a means of confirming the accuracy of the results. This can be seen with the issue of work overload which became evident with the qualitative data. Although not evident in the questionnaire on burnout, the factor “self criticism regarding no time for family and meaningful activities” was the only factor to show no improvement, indirectly suggesting that work was interfering with their private life.

These examples show how evidence can be incomplete without drawing from diverse sources (Long, et al., 2006; Moriarty, et al., 2007; Billings, 2013).

6.5 LIMITATIONS

Several limitations were also encountered and these will be discussed chronologically as they appeared in the study.

The Quantitative study

Although, as mentioned in the methodology, randomised trials have been accepted as the most robust, this was not used in this study, because it was not considered ethical to offer a beneficial intervention to half the team and not to the other half (Harris, et al., 2006), and although the intervention had not been scientifically evaluated at the time of implementation, it had previously been given to a large number of HCWs, with positive verbal feedback. Ewers et al. (2002)

and Doyle (2007) overcame this problem by allocating half the personnel of each team to the experimental group and using the other half as a control group, then subsequently giving the intervention to the control group. However, due to timing and funding limitations, this was not possible.

Practical reasons were also a detriment to carrying out a randomized trial. As in the study by Ewers et al. (2002), where all the nurses had volunteered to participate and were of a specialised nature and small in numbers, it was not possible in this present study to randomly choose the participants, because permission was required from the clinical directors of each team, and then each team member had to agree to participate leaving only a limited amount of participants available. Although 22 units were contacted to participate in the intervention it was not possible to foresee how many would accept.

The validation of the questionnaires did not include the results of the sensitivity tests, as these were only performed for future use of the questionnaires. The validation analyses were performed with participants from the control and the experimental groups, and therefore, the items that were subsequently eliminated from the questionnaire were used before the intervention and for this reason, to enable correct comparison between questionnaires, they were also kept for analyses after the intervention.

There was a limitation in this study in the uneven distribution of participants — in particular, the majority were female, and were nurses or nursing aides. However, this gender imbalance does reflect the reality in most health care institutions and the latest statistical information on the nursing workforce in Portugal shows that 81 percent of nurses are female (Ordem dos Enfermeiros (Nurses Association of Portugal), 2010).

For reasons mentioned earlier, the control group was limited to 26 people, and of the study’s 150 participants, only 65 were comparable to the control group (those caring for patients with a terminal condition outside of palliative care units). With hindsight, and had the process been started earlier, it may have been possible to obtain a significantly larger control group using a different yet effective method which is the snowball method, where participants were asked to invite a colleague with the same characteristics as themselves in terms of age and work experience (Adriaansen, et al., 2005). Furthermore, the control group was limited to those working in other units. However, quantitative results and qualitative feedback on the benefits of the intervention would seem to confirm that the changes that occurred were not due only to the passing of time.

Within this research, the initial sample consisted of 208 participants, but only 150 completed both sets of questionnaires, and these participants were not randomized. It is therefore difficult to assess whether the sample is representative of the whole of Portugal. However, geographically, participants came from the south, centre, and north of Portugal.

The study used self-report instruments with no objective form of measurement, although anonymity was guaranteed and the importance of truthful answers was stressed.

While the study design of quasi experimentation allowed for these design gaps to some extent, due to weaknesses in the control group, lack of randomisation, and potential bias in sample selection, the study results must be treated with caution and cannot be generalisable. However, research in the real world of social sciences is often not possible in a controlled environment and this method did enable research in this area to be undertaken, maintaining an experimental format (Robson, 2002).

Delivery of the intervention

As mentioned previously, in this project, two separate trainers with different background trainings gave the course. The first part of the course, which involved more therapy, was given by a counsellor trained in the Person Centred Approach, and the second trainer used a more psychodynamic approach. This meant that sometimes, interpretations were made regarding the participant's feelings and opinions. This is a normal approach in psychodynamics, but it is never used in the Person Centred Approach. Occasionally, this difference in therapeutic approach was felt by the participants and caused some confusion. If training was undertaken in the future, this should be given by one therapist only, or if there are two therapists, it is recommended that they have the same background in psychotherapy and the same approach to the training exercise. Moreover to reduce bias to the minimum, there should ideally be the separation of the roles of therapist and researcher. Within the limits of this study, this was not possible.

As the separaton of roles was not possible, there could be a concern that the facilitator played the dual role of therapist and researcher. It was necessary at the time to have this dual role for otherwise the role of the researcher would have been limited to carrying out the interviews and analysing data. It was important therefore, that the researcher/therapist remain impartial throughout the study. No tension was felt during the first part of the intervention, when the researcher also carried out the role of therapist, as training in Person Centred Psychotherapy provides ample experience in remaining centred on the client and simultaneously maintaining awareness of oneself, enabling the researcher to refrain from any temptation to promote the benefits of the intervention. Furthermore, the intervention was given at one stage and data analysis at another time and this distinction was made very clear to the participants in the study. However, tension was apparent during the interviews, because the researcher was aware that participants may be excessively positive about the intervention due to the therapeutic relationship created. Special care was taken to explain before the interview that negative feedback would be equally important in order to improve the intervention and there was the intent to remind participants of this if they seemed apologetic or reluctant to be completely frank.

Although a diary was kept of each intervention, the purpose of this was to register therapeutic notes of the group and each member. Sometimes reflexive notes about the author's performance were taken, but this was not performed systematically, and was not discussed with a supervisor. In hindsight, a complete reflexive diary should have been kept together with regular supervision to help the researcher set aside any presumptions, preconceived ideas and biases, which would have potentially made the research process more neutral (Lincoln & Guba, 1985). There is therefore the potential of not having had a faifthful representation of the data, which could have been overcome with a more rigorous supervision of techniques.

The Qualitative Study

During the intervention

At the beginning of each intervention, the facilitator asked the group to talk about their difficulties in caring for the dying. As they spoke, these were written on the board and taken note of during the morning interval. Sometimes their own expressions were used, but most of the time, short sentences were used. For example “feeling helpless”, “what to say when the person talks of death”, “dealing with silences”. This information could have been richer if it had occurred within the format of recorded focus groups with a more detailed content analysis. Also, the accuracy of note taking is at issue. This could have been overcome to some extent by reading notes back to respondents after the sessions to ascertain content validity (Pope & Mays, 2006).

Furthermore, the profession of who made the comments was not written down at the time, and if more than one participant in the group mentioned the same problem, the researcher wrote a number next to the comment. This made it possible to understand what the main difficulties were, but not to understand if some professional categories had more difficulties than others. So this impacted on the richness and accuracy of the data for these sessions.

Face to face interviews:

The tape recorder was switched on after a few words of introduction to put the participant at ease and was switched off after the main interview had taken place. However, very often, the participants relaxed after the interview was over and the conversation became more informal and valuable information was lost. In hindsight, although the interview was officially over, the tape should only have been switched off only once the participant had left the room.

Upon rereading some of the interviews, it became apparent that the researcher is also an ‘instrument’ during the interviews, with the capacity to shape the research process (Lincoln & Guba, 1985). It is important not to influence the interview in any way, and although the interviewer was aware of this, there were occasions when some of the answers were directive. An example of this can be seen in the interview example in appendix 28, in the sentence “This bad atmosphere, does it affect your work”. This type of leading quetion would induce the participant to talk about problems at work. Had the question been phrased “What are the consequences of this bad atmosphere, if any?” the participant may have chosen to talk about work, but may also have chosen to talk about how it affects her/his personal life, or may have answered that it had no effect.

In addition, having different qualitative data sources meant that there was an imbalance between data collected at different phases of the research and between different professionals. These deficiencies therefore had the potential to affect the quality and interpretation of the data.

Trustworthiness of qualitative data

The credibility of the qualitative study could have been improved had in-depth field notes been kept. As mentioned in the previous section on the limitations of the delivery of the intervention, field notes were kept, but the purpose of these were to increase the quality of the psychotherapy provided, and not as a reflexive exercise to assess the academic quality of the research. Furthermore, regular meetings with a supevisor before and after the intervention and interviews would also have helped to increase academic rigour. The frequency of these meetings was hindered because the research took place in Portugal, where the author also lives and both supervisors lived in the UK.

7. CONCLUSIONS AND RECOMMENDATIONS

The aim and contribution of this project was to understand whether an intervention designed specifically for HCWs who care for patients with a terminal condition, would help reduce their death-related fears, increase their existential well-being and the perception of their own competence in their helping relationship skills and as a consequence, reduce burnout and increase their capacity to engage in an effective helping relationship.

The main conclusions

The intervention did lead to a significant improvement in levels of personal well-being, perception of their own competencies in helping relationship skills and a reduction in levels of burnout. An exception was in “self-criticism regarding no time for family and meaningful activities”, which was related to work overload.

The qualitative results supported the quantitative results and were fundamental to understand and correctly interpret the findings. For example, they seemed to show higher levels of burnout than initially indicated by the quantitative results, and a more in-depth study of the items of the burnout questionnaire showed that the causes that lead to burnout in end of life care are different from those of general burnout.

This interactive training intervention, with a limited number of participants, and which focuses on both the patient and the HCW’s needs, was considered useful by the participants, and did effectively accomplish what it aimed to do.

Education in communication and in providing psychological and spiritual support to patients, along with personal introspection related to death anxiety, may help HCWs who care for patients with a terminal condition to reduce their need to protect themselves by avoiding meaningful helping relationships with patients.

A six-day intervention did provide training and an increase of awareness of the issues involved in the care of the dying patient and their family but the course was insufficient to create sustained long term results. In Portugal, most HCWs who care for patients with a terminal condition in palliative care units would normally have training in palliative care, but the training and personal preparation provided in the present intervention, to cope with death and dying is not given in any of the palliative care trainings. To obtain sustained results, this needs to be combined with ongoing supervision and support.

The qualitative feedback also showed that personnel are very tired due to the lack of staff, work overload, conflicts within the team and difficulties at an institutional level. This has implications for the development of palliative care in Portugal and palliative care providers need to be aware of the risks of developing services without the support of the clinical team.

Recommendations

For palliative care units who have already provided their personnel with specialist palliative care training, this intervention may be given as a complementary module to help HCWs cope with death anxiety and personal existential issues that also affect patients with a terminal condition. This will prepare them with the emotional capacity to put into practice the specific helping relationship skills given in the second part of the intervention.

For other units who care for patients with a terminal condition without any palliative care training, this intervention is essential for the same reasons. However, this module should then be complemented with specific training in pain control and symptom management.

Further work is needed to develop the new framework for the prevention of burnout in end of life care.

As well as the benefits received from this intervention, HCWs who care for patients with a terminal condition and their families, both in palliative care units and in other units, would benefit from a continuous support system within the institution. The general feedback continues to be that HCWs who care for patients with a terminal condition in Portugal have no type of emotional support, and this intervention should be provided to all HCWs by the institution and followed up by regular sessions for emotional support.

Recommendations for future research

HCWs who care for patients with a terminal condition in Portugal do not have an organized emotional support system within the institution and are basically left to fend for themselves. There is, therefore, a strong need for more investigation in this area in order to create positive changes within Portugal's national health system. However, in order to present a convincing case to the Ministry of Health and hospital administrations, research is needed containing objective data, rather than the participants' subjective view of their performance. This could be done through further study of the effectiveness of emotional support by providing training and continuous support to a larger variety of institutions, and it could include an evaluation of the physical and objective signs of HCWs' burnout, such as physical symptoms, absenteeism, staff turnover, and team conflicts, and its concrete consequences for the institution. A similar study has been performed by Borritz et al. (2006), with 824 participants from different human service sector organisations over three years. The aim was to investigate whether burnout predicted sickness absence days and sickness absence spells in human service workers (not just HCWs who care for patients with a terminal condition). Their findings indicated that burnout predicts sickness absence and that therefore, reducing burnout is likely to reduce sickness absence. It would be useful however to take this one step further and analyse the consequences in terms of the institutions' credibility and reputation as well as the financial costs that can result from burnout.

When considering death anxiety, questionnaires measuring this concept were found, but the items did not seem to be closely linked to the existential fears of dying unlike the items used in this research. Death anxiety was measured by combining the questionnaire on well-being and some questions from the Barrett-Lennard Inventory. It would be useful to create and validate a separate instrument specifically to measure death anxiety that combines the items of these two questionnaires.

Further research looking at the framework for burnout in end of life care would be helpful, to confirm the suggestions for the framework.

Further studies could be undertaken to ascertain if an intervention to allow HCWs to look more closely at the work they do and to develop themselves personally not only reduces the risk of burnout but does improve the care to their patients and families.

BIBLIOGRAPHY

Abdel-Khalek, A., 2002. Why do we fear death? the construction and validation of the reasons for death fear scale. *Death Studies - Bruner-Routledge,* pp. 26:6697680, pg 21.

Abendroth, M. & Flannery, J., 2006. Predicting the Risk of Compassion Fatigue. *Journal of Hospice and Palliative Nursing,* pp. vol 8, Nº 6 Nov/Dec.

Abu-Hilal, M. & Salameh, K., 1992. Validity and realiability of the Maslach Burnout Inventory for a sample of non-western teachers. *Educational and Psychological Measurement,* p. 52.

Adriaansen, M., Achterberg, T. v. & Borm, G., 2005. Effects of a postqualification course in palliative care. *Journal of Advanced Nursing,* 49(1), pp. 96-103.

Ahola, K. et al., 2008. Occupational burnout and medically certified sickness absence: A population-based study of Finnish employees. *Journal of Psychosomatic Research,* pp. vol 64, Issue 2, pg 185-193.

Aitken, H., 2011. *Vie et Mort, la même préparation.* [Online]
Available at: https://sites.google.com/a/hermineaitken.com/soins-a-doublesens/
[Accessed 27 10 2011].

Alacacioglu, A. et al., 2009. Burnout in nurses and physicians working at an oncology department. *Psycho-Oncology,* pp. 18: 543-548.

Albom, M., 2003. *Tuesdays with Morrie.* London: Time Warner Paperbacks.

Alderson, P., 1998. The importance of theories in health care. *British Medical Journal,* 3(17), pp. 1007-10.

Alexander, D. A. & Klein, S., 2000. Bad news is bad new: lets not make it worse. *Trauma,* Volume 2, pp. 11-18.

Allegra, C. J., Hall, R. & Yothers, G., 2005. Prevalence of Burnout in the U.S. Oncology community: Results of a 2003 Survey. *Journal of Oncology Practice,* pp. 140-147.

Andrews, J., Manthorpe, J. & Watson, R., 2005. Nursing and Health Care Management and Policy. Employment transitions for older nurses: a qualitative study. *Journal of Advanced Nursing,* 51(3), pp. 298-306.

Antonovsky, A., 1987. *Unraveling the Mystery of Health.* San Francisco: Jossey-Bass.

APEME, 2008. *Área de Planeamento e Estudos de Mercado,* s.l.: Os Cuidados Paliativos em Portugal.

Aronson, E., 2011. *The Social Animal.* Eleventh ed. New York: Worth Publishers.

Arrindell, W. & Ende, J. v. d., 1985. An empirical test of the utility of the observer-to-variables ratio in factor and components analysis. *Applied Psychological Measurement,* Issue 9, pp. 165-178.

Asai, M. et al., 2007. Burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients: A cross-sectional nationwide survey in Japan. *Psycho-Oncology,* pp. 16: 421-428.

Associação Portuguesa de Cuidados Paliativos, accessed on 22.8.2012. Equipas de Cuidados Paliativos. Issue http://www.apcp.com.pt/cuidadospaliativos/equipasdecuidadospaliativos.html.

Back et.al., 2005. Approaching difficult communication tasks in oncology. *CA Cancer J Clin,* pp. 55;164-177.

Bakker, A. B. & Demerouti, E., 2008. Towards a model of work engagement. *Career Development International,* 13(3), pp. 209-223.

Barrett-Lennard, G., 1964. *The relationship inventory form OS-M-64 and OS-F-64 Form MO-M-64 and MO-F-64.* Australia: University of New England (First Printing).

Barrett-Lennard, G., 1978. The Relationship Inventory: Later development and applications. *JSAS:Catalog of Selected Documents I Psychology,* pp. 8, 68 (Ms. Nº 1732, pp 55).

Barroso, I. M. d. C., 2009. *O Ensino Clínico no Curso de Licenciatura em Enfermagem,* Porto: Instituto de Ciências Biomédicas Abel Salazar - Universidade do Porto.

Bartlett, J. E., Kotrlik, J. & Higgins, C. C., 2001. Organizational Research: Determining Appropriate Sample Size in Survey Research. *Information Technology, Learning and Performance Journal,* 19(1 Spring).

Bartlett, M., 1954. A note on the multiplying factors for various chi square approximations. *Journal of the Royal Statistical Society,* pp. 16 (Series B), 296-8.

Batista, P., 2011. *Stress e Coping nos Enfermeiros dos Cuidados Paliativos em Oncologia,* Porto: Repositório aberto Universidade do Porto.

Bazeley, P., 2002. Computerized Data Analysis for Mixed Methods Research. Em: A. T. a. C. Teddlie, ed. *Handbook of Mixed Methods for the Socical and Behavioural Sciences.* Thousand Oaks CA.: SAGE, pp. 385-422.

Beck, C.T. 1993. Qualitative Research: the evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research,* 15(2), pp. 263-266

Bennett, R., 1976. Attitudes of the Young toward the Old: a Review of Research. *Personnel and Guidance Journal,* Issue November.

Bentler, P., 1995. *EQS: Structural equatrions program manual.* Encino CA: Multivariate Software.

Bergin, M., 2011. NVivo 8 and consistency in data analysis: reflecting on the use of a qualitative data analysis program. *Nurse Researcher,* 18(3), pp. 6-12.

Bernard, M. & Creux, F., 2003. Suffering - a problem that also affects nurses. *European Journal of Palliative Care,* pp. 10(2): 77-81.

Berthon, M., Pronost, A. & Tap, P., 1996. Stress, coping et épuisement professionel (burnout) chez les infirmières chargées de personnes en fin de vie. *Aprendizagem e Desenvolvimentos,* pp. vol IV nº 15/16 pg 157-164.

Billings, J., 2009. *What counts as evidence in INTERLINKS? Discussion Paper# 4,* s.l.: European Commission.

Billings, J., 2013. Improving the evidence base. Chapter 14 in Leichsenring, K. Billings, J & Nies, H.. In: *Long Term Care in Europe - Improving Policy and Practice.* Basingstoke: Palgrave Macmillan, pp. 299-324.

Blanche, M., 1997. Running a hospice staff support course. *European Journal of Palliative Care,* pp. 4(6): 200-202.

Blomberg, K. & Sahlberg-Blom, E., 2007. Closeness and distance: a way of handling difficult situations in daily care.. *Journal of Clinical Nursing. Blackwell Publishing Ltd,* pp. 16, 244-154.

Bonnin-Scaon, S., Colombat, P., 2007. Démarche palliative et prévention de la souffrance des soignants. *Oncologie,* pp. 10: 113-115.

Borritz, M., Rugulies, R. Christensen, K.B., Villadsen, E., Kristensen, T.S., 2006. Burnout as a predictor of self-reported sickness absence among human service workers: prospective findings of three year follow up of the PUMA study. *Occup Environ Med,* pp. 63:98-106.

Braun, M., Gordon, D. & Uziely, B., 2010. Association between Oncology Nurses' Attitudes Toward Death and Caring for dying Patients. *Oncology Nursing Forum,* pp. vol 37, Nº 1.

Bressi, C. et al., 2008. Haemato-oncology and burnout: an Italian survey. *British Journal of Cancer,* pp. 98, 1046-1052.

Brill, P., 1984. The need for an operational definition of burnout. *Family and Community Health,* pp. vol 6, 12-24.

Bruder, M., 1994. Working with members of other disciplines: Collaboration for success.. Em: *Including children with special needs in early childhood programs.* Washington DC: National Association for the Education of Young Children: M Wolery & J.S. Wilbers (Eds), pp. 45-70.

Burger, A., 1995. Burnout-what is at stake. *European Journal of Palliative Care,* pp. 2(1): 33-34.

Byock, I., 1996. The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine,* pp. vol 12, Nº 2, pp 237-251 May.

Byock, I., 2004. *The Four Things that Matter Most.* New York: Free Press.

Campbell, D. & Stanley, J. C., 1963. *Experimental and Quasi-Experimental Designs for Research.* Boston: Houghton Mifflin company.

Catell, R., 1966. The scree test for numbers of factors. *Multivariate Behavioural Research,* pp. 1, 245-76.

Centeno, C. et al., 2007. *EAPC Atlas of Palliative Care in Europe.* Milan: EAPC.

Charmaz, K., 2006. *Constructing Grounded Theory. A practical guide through qualitative analysis.* CA: Sage: Thousand Oaks.

Chenitz, W. & Swanson, J., 1986. *From practice to grounded theory: Qualitative research in nursing..* Menlo Park, California:Addison-Wesley: s.n.

Cherniss, C., 1980a. Staff Burnout: Job Stress in the Human Services. In: Beverly Hills, CA: Sage, p. 5.

Cherniss, C., 1980b. Professional burnout in Human Service Organizations. Em: New York: Praeger.

Cherniss, C., 1992. Long-term consequences of burnout: an exploratory study. *Journal of Organizational Behaviour,* pp. vol 13, 1-11.

Chevalier, accessed 2012. *http://www.great-inspirational-quotes.com/aging-quotes.html. accessed 17.3.2012,* s.l.: s.n.

Chiovitti, R.F. & Piran, N., 2003. Rigour and grounded theory research. *Journal of Advanced Nursing.* 44(4). pp. 427-435

Chow, A., 2011. Prevention of burnout and compassion fatigue through education and training: the project ENABLE. Em: *Caregiver Stress and Staff Support in Illness, Dying, and Bereavement.* Oxford: Oxford University Press, pp. pp 98-110.

Chow, A. Y., 2013. Developing Emotional Competence of Social Workers of End-of-Life and Bereavement Care. *British Journal of Social Work,* Volume 43, pp. 373-393.

Coatsworth, P., McBride, B. & Kurtines, S., 2000. Ecodevelopmental correlates of behavior problems in young hispanic adolescents. *Applied Development Science,* Volume 6, pp. 126-146.

Cochran, W., 1977. *Sampling techniques (3rd ed.).* New York: John Wiley & Sons.

Committee on National guideline for Palliative Sedation, 2009. *Guideline for Palliative Sedation,* Utrecht, NL: Royal Dutch Medical Association (KNMG).

Comrey, A. & Lee, H., 1992. *A first course in factor analysis (2nd edition).* Hillsdale: NJ: Erlbaum.

Connelly, J., 2009. The avoidance of human suffering. *Perspectives Biol Med,* pp. 52(3): 381-391.

Cook, D. A. & Beckman, T. J., 2008. Reflections on experimental research in medical education. *Adv in Health Sci Educ.*

Cordes, C. & Dougherty, T., 1993. A review and an integration of research on job burnout. *Academy of Management Review.*

Costantini, M. et al., 2003. Effect of a palliative home care team on hospital admissions among patients with advanced cancer. *Palliative Medicine,* Volume 17, pp. 315-321.

Crawford, G. & Price, S., 2003. Team Working: palliative care as a model of interdisciplinary practice. *Med J Aust,* pp. 179: S32-34.

Creswell, J., 1998. *Qualitative inquiry and research design: Choosing among five traditions.* Sage ed. CA: Thousand Oaks.

Crowley, C., Harre, R. & Tagg, C., 2002. Qualitative researcy and computing: Methodological issues and practices in using QSR NVivo and Nud*ist. *International Journal of Social Research Methodology,* 5(3), pp. 193-197.

Currow, D. & Hegarty, M., 2006. Suffering at the bedside of the dying. *Journal of Religion, Spirituality and Aging. The Haworth Pastoral Press Inc.,* pp. vol 18, Nº 2/3, pp. 123-136.

De Dreu, C. & Weingart, L., 2003. Task versus relationship conflict, team performance, and team member satisfction: a meta-analysis.. *Journal of Applied Psychology,* pp. 88: 741-49.

De Jonge, J. & Kompier, M., 1997. A critical examination of the Demand-control-Support Model from a work psychological perspective. *International Journal of Stress Management,* Volume vol 48, pp. 1149-60.

DECO, 2011. Cuidados Paliativos em Portugal sem capacidade de resposta. *http://www.rcmpharma.com/actualidade/saude/cuidados-paliativos-em-portugal-sem-capacidade-de-resposta_234,* p. 23/5/2011 accessed on 20.2.12.

DECO-Defesa do Consumidor, 2011. Doentes terminais: mais dignidade no adeus. *http://www.deco.proteste.pt/servicos-de-saude/doentes-terminais-mais-dignidade-no-adeus-s645501.htm,* p. May. Accessed on 20/2/2011.

Delvaux, N., Razavi, D. & Marchal, S., 2004. Effects of a 105 hours psychological training program on communication skills and occupational stress in oncology: a randomised study.. *Br J Cancer,* pp. 90(1); 106-114.

Demerouti, E., 1999. *Burnout: a consequence of specific working conditions in human services and production work.* Frankfurt/Main: Peter Lang.

Demerouti, E., Bakker, A., Nachreiner, F. & Schaufeli, W., 2000. A model of burnout and life satisfaction amongst nurses. *Journal of Advanced Nursing,* pp. 32(2), 454-464.

Demerouti, E., Bakker, A., Nachreiner, F. & Schaufeli, W., 2001. The job demands-resources model of burnout. *Journal Applied Psychology,* Volume Jun; 86(3), pp. 499-512.

Department of Health, Melbourne, Victoria, 2010. *Value added: the wisdom of older nurses at work,* Melbourne: Workforce Leadership and Development Branch, Victorian Government.

Diário de Notícias, 2011. O que vai ser cortado na saúde. *Diário de Notícias*, 02 September, pp. http://www.deficiente-forum.com/index.php?topic=21671.0.

Dickenson, D., 2007. End-of-life and palliative care issues in medical and nursing schools in the United States. *Death Studies,* pp. 31:713-726.

Direction Générale de la Santé, 2002. *Circulaire DHOS/O 2/DGS/SD 5 D n° 2002-98 du 19 février 2002 relative à l'organisation des soins palliatifs et de l'accompagnement, en application de la loi n° 99-477 du 9 juin 1999, visant à garantir le droit à l'accès aux soins palliatifs.* [Online]
Available at: http://www.sante.gouv.fr/IMG/pdf/Circulaire_DHOS-DGS_no2002-98_du_19_fevrier_2002_presentant_les_differentes_modalites_de_pratique_des_soins_palliatifs.pdf
[Accessed 20 March 2012].

DiTullio, M. & MacDonald, D., 1999. The struggle for the soul of hospice: Stress, coping and change among hospice workers. *American Journal of Hospice and Palliative Medicine,* pp. vol 16, Nº 5, September/October.

Doef, M. v. d. & Maes, S., 1999. The Job Demand-control (-Support) Model and psychological well being: a review of 20 years of empirical research. *Work and STress,* Volume 13, pp. 87-114.

Doyle, M., 2007. Burnout: the impact of psychosocial interventions training: Can equipping mental health workers with the skills to integrate psychosocial interventions into practice cut levels of burnout among staff?. *Mental Health Practice,* 10(7).

Dunwoodie, D. & Auret, K., 2007. Psychological morbidity and burnout in palliative care doctors in Western Australia. *Internal Medicine Journal,* p. 37 (2007) 693–698.

Ebbinghaus, M., 1996. *Conceptualizing burnout: development and validation of a measurement instrument for application in various working domains,* Oldenburg, Germany: unpublished manuscript, Department of Work and Organizational Psychology, University of Oldenburg.

Edelwich, J. & Brodsky, A., 1980. Burnout: Stages of disillusionment in the helping professions. Em: New York: Human Services Press.

Elder, N., Ricer, R. & Tobias, B., 2006. How respected family physicians manage difficult patient encounters. *JABFM,* pp. Nov-Dec vol 19 Nº 6.

Emold, C., Schneider, N., Meller, I. & Yagil, Y., September 2011. Communication skills, working environment and burnout among oncology nurses. *European Journal of Oncology Nursing,* pp. vol 15, Issue 4, Pasges 358-363.

Ewers, P., Bradshaw, T., McGovern, J. & Ewers, B., 2002. Does training in psychosocial inteventions reduce burnout rates in forensic nurses?. *Journal of Advanced Nursing,* Volume 37(5), pp. 470-476.

Farber, N., Novack, D. & O'Brien, M., 1997. Love, boundaries, and the patient-physician relationship. *Arch Internal Medicine,* pp. 157: 2291-2294.

Fawzy, F., Fawzy, N. & Pasnau, R., 1991. Burnout in the health professions. In: F. Judd, G. Burrows & D. Lipsitt, eds. *Handbook of studies on general hospital psychiatry.* s.l.:Elsevier, p. chapter 9.

Figley, C., 1995. *Compassion Fatigue: Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized.* New York: Brunner/Mazel;.

Figley, C., 2002. *Treating Compassion Fatigue.* New York: Brunner-Routledge.

Fillion, L., Duval, S, Dumont, S. Gagnon, P. Tremblay, I., Bairati, I. Breitbart, W., 2009. Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care `nurses. *Psycho-Onchology,* pp. 18: 1300-1310.

Fillion, L., Fortier, M. & Goupil, R., 2005. Educational needs of palliative care nurses in Quebec. *J Palliative Care,* pp. 21(1): 12-18.

Fillion, L. & Saint-Laurent, L., 2003. *Stressors linked to palliative care nursing: the importance of organizational, professional and emotional support,* Québec: Canadian Health Services Research Foundation.

Fillion, L. et al., 2007. Job Satisfaction and Emotional Distress Among Nurses Providing Palliative Care: Emprirical Evidence for an Integrative Occupational Stress Model. *International Journal of Stress Management,* pp. vol 14, No. 1, 1-25.

Filliozat, A. G. G., 2006. *Aide-toi, tons corps t'aiderá.* s.l.:Editions Clés, Michel Albin.

Fineberg, I., 2005. Preparing Professionals for Family Conferences in Palliative Care: Evaluation results of an interdisciplinary Approach. *Journal of Palliative Care,* 8(4).

Finlay, I., 1989. Sources of stress in hospice medical directors and matrons. *Palliative Medicine,* Volume 4, pp. 5-9.

Florio, G., Donnelly, P. & Zevon, M., 1998. The structure of Work-Related Stress and Coping Among Oncology Nurses in High-Stress Medical Settings: A Transactional Analysis. *Journal of Occupational Health Psychology,* pp. vol 3, No. 3, 277-242.

Frankl, V. E., 1963. *Man's Search for Meaning.* 27th ed. New York: Pocket Books.

Fraser Health, End of Life Care, Quality Performance Council, 2011. Refractory Symptoms and Palliative Sedation Therapy Guideline. *Hospice Palliative Care Programm Symptom Guidelines,* pp. 4, 5.

Freudenberger, H., 1974. Staff burnout. *Journal of Social Issues,* pp. 30 pp 159-165.

Freudenberger, H., 1975. The staff burnout syndrome in alternative institutions. *Psychotherapy: Theory, Research and Practice,* pp. 12, 73-82.

Freudenberger, H., 1980. *Burnout: the cost of high achievement.* New York: Ancho Press.

Freudenberger, L. & Canter, M., 2001. Herbert J. Freudenberger (1026-1999). *American Psychologist,* p. vol 56 nº 12.

Friedrichsen, M. & Milberg, A., 2006. Concerns about losing control when breaking bad news to terminally ill patients with cancer: Physicians' perspective. *Journal of Palliative Medicine,* pp. vol 9, Nº 5.

Frommelt, K., 1991. The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. *American Journal of Hospice and Palliative Care,* Sep-Oct(8(5)), pp. 37-43.

Gahan, C. & Hannibal, M., 1998. *Doing qualitative research using QSR NUD*IST.* London: SAGE.

Gamondi, C., Larkin, P. & Payne, S., 2013. Core competencies in palliative care: an EAPC White Paper on palliative care education - part 1. *European Journal of Palliative Care,* 20(2), pp. 86-91 .

Gibbs, G., 2004. Searching for Text. Em: C. Seale, ed. *Social Research Methods: A reader.* London: Routledge, pp. 307-311.

Glasby, J. & Beresford, P., 2006. Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy,* 26(1), pp. 268-284.

Glaser, B. & Strauss, A., 1967. *The Discovery of Grounded theory: Strategies for Qualitative Research.* New York: Aldine.

Gold, Y., Bachelor, P. & Michael, W., 1989. The Dimensionality of a modified form of the Maslach Burnout Inventory for university students in a teacher-training program. *Educational and Psycholoigcal Measurement.*

Gouveia e Melo, C., 2003. *A relação de ajuda com doentes com uma doença grave, evolutiva ou terminal - compreender as dificuldades do doente e o burnout no profissional de saúde, ilustrado com um estudo de investigação com doentes com SIDA, no hospital Curry Cabral,* Lisboa: Unpublished Post-Graduate thesis in library of ISPA-Insituto Universitário.

Gouveia e Melo, C. & Oliver, D., 2012. Assessing burnout in portuguese health care workers who care for the dying:validity and reliability of a burnout scale using exploratory factor analysis. *Psychology, Community & Health,* Volume 1(3), pp. 257-272.

Graeff, A. d. & Dean, M., 2007. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. *Journal of Palliative Medicine,* Volume 10(1), pp. 67-85.

Greene, G., 1960. *A Burnt Out Case.* United Kingdom: Heinemann.

Greene, J., 1990. *Methodology Handbook.* 4th ed. Milton Keynes: The Open University.

Green, J. & Thorogood, N., 2004. *Qualitative Methods for Health Research.* CA: Sage: Thousand Oaks.

Grimshaw, J., Campbell, M., Eccles, M. & Steen, N., 2000. Experimental and quasi-experimental designs for evaluating guideline implementation strategies. *Family Practice,* pp. 17: S11-S18.

Guadagnoli, E. & Velicer, W., 1988. Relation of sample size to the stability of component patterns. *Psychological Bulletin,* Issue 103, pp. 265-275.

Guba, E., 1981. Criteria for assessing the trustworthiness of naturalistic inquiries. Volume 29, pp. 75-91.

Guba, E.G. & Lincoln, Y.S. 1989. *Fourth Generation Evaluation.* Sage Publications, Newbury Park CA

Haas, L., Leiser, J. & Magill, M. S. O., 2005. Management of the Difficult Patient. *American Family Physician,* pp. Nov 15, vol 72 Nº 10.

Halbesleben, J. R. & Demerouti, E., 2005. The construct validity of an alternative measure of burnout: Investigating the English translation of the Oldenburg Burnout Inventory. *Work & Stress,* July-September 19(3), pp. 208-220.

Halpern, J., 2007. Empathy and Patient-Physician Conflicts.. *Society of General Internal Medicine,* pp. 22:696-700.

Harris, A., McGregor, J. C. & Perencevich, E., 2006. The use and interpretation of quasi-experimental studies in medical informatics. *Journal of the American Medical Informatics Association,* 13(1 Jan/Feb).

Hegedus, K., Zana, Á. & Szabó, G., 2008. Effect of end of life education on medical students' and health care workers' death attitude. *Palliative Medicine,* pp. 22: 264-269.

Hennezel, M. d., 1998. Intimate Distance. *European Journal of Palliative Care,* p. 5(2).

Hennezel, M. d., 2012. *Marie de Hennezel.* [Online]
Available at: http://www.toslog.com/mariedehennezel/livres
[Accessed 20 March 2012].

Hennezel, M. d. & Leloup, J. Y., 1997. *L'art de mourir: traditions religieuses et spiritualité humaniste face à la mort..* Paris: Robert Laffond.

Hipólito, J., .2012. *Curriculum Vitae João Hipólito.* [Online]
Available at: http://www.gatf.pt/cvjoaohipolito.htm
[Accessed 5 1 2012].

Hjöleifsdóttir, E. & Carter, D. E., 2000. Communicating with terminally ill cancer patients and their families. *Nurse Education Today,* pp. 20,646-653.

Holland, J. M. & Neimeyer, R. A., 2006. Reducing the risk of burnout in end-of-life care settings: the role of daily spiritual experiences and training. *Palliative and Supportive Care,* Volume 3, pp. 173-181.

HSE Clinical Strategy and Programmes Directorate, May 2013. Glossary of Terms. *Palliative Care Programme.*

Hull, S. & Broquet, K., 2007. How to manage difficult patient encounters. *Family Practise Management,* p. www.aafp.org/fpm June 2007.

Human Research Ethics Office, 2008. *Guidelines for Ethics in Dual Role Researcher for Teachers and other Practitioners,* Victoria, Ca.: University of Victoria.

Jackson, S. E., Schwab, R. & Schuler, R., 1986. Toward an Understanding of the Burnout Phenomenon. *Journal of Applied Psychology,* pp. vol 7, Nº 4 630-640.

Jackson, V. A. et al., 2008. A Qualitative Study of Oncologists' Approaches to End-of-Life Care. *Journal of Palliative Medicine,* 11(6).

Jerabek, I., 2001. *Burn-out Test (Service Fields).* http://testyourself.psychtests.com/testid/2079: PsychTests Aim Inc.

Johnson, J. & Hall, E., 1988. Job strain, work place social support, and cardiovascular disease-a cross sectional study of a random sample of the Swedish working population. *American Journal of Public Health,* Volume 78, pp. 1336-1342.

Johnson, J. H. E. &. T. T., 1989. Combined effects of job strain and social isolation on cadiovascular disease morbidity and mortality in a random sample of Swedish male working population. *Scandinavian Journal of Work, Environment and Health,* pp. 15, 271-279.

Johnson, J. V. & Hall, E., 1988. Job Strain, work place social support, and cardiovascular disease: A cross-sectional study of a random sample of the Swedish working population. *American Journal of Public Health,* pp. 78, 1336-1342.

Joinson, C., 1992. Coping with compassion fatigue. *Nursing,* pp. 22(4): 116-121.

Jones, A., 1998. Some reflections on clinical suspervision: an existential-phenomenological paradigm. *European Journal of Cancer Care,* pp. 56-62.

Jones, A., 2008. Towards a common purpose: group-format clinical supervision can benefit palliative care. *European Journal of Cancer Care,* Volume 17, pp. 105-106.

Jones, A., 2009. Returning meaning to palliative care staff.. *European Journal of Palliative Care,* p. 16(4).

Jornal de Notícias, 2012. Médicos vão ter formação específica em cuidados paliativos. *Jornal de Notícias*, 29 May, p. http://www.jn.pt/PaginaInicial/Sociedade/Saude/Interior.aspx?content_id=2553292&page=1.

Jünger, S. & Payne, S., 2011. Guidance on postgraduate education for psychologists involved in palliative care. *European Journal of Palliative Care, 2011; 18(5),* Volume 18(5), pp. chapter 3,7 pg 246.

Jünger, S., Pestinger, M., Krumm, F. & Radbruch, L., 2007. Criteria for successful multiprofessional cooperation in palliative care teams. *Palliative Medicine,* pp. 21: 347-354.

Kain, J. & Jex, S., 2010. Karasek's (1979) Job demands-control model: a summary of current issues and recommendations for future research. Em: P. L. P. a. D. C. Ganster, ed. *New Developments in theorectical and Conceptual Approaches to Job Stress.* Bingley, UK: Emerald Group Publishing Limited, pp. 237-268.

Kaiser, H., 1970. A second generation Little Jiffy. *Psychometrika,* pp. 35, 401-15.

Kaiser, H., 1974. An index of factorial simplicity. *Psychometrika,* pp. 39, 31-6.

Kalliath, T. J., 2000. A test of the Maslach Burnout Inventory in three samples of healthcare professional. *Work & Stress,* Volume 14, pp. 35-51.

Karasek, R., 1979. Job demands, job decision latitude, and mental strain: implications for job design. *Administrative Science Quarterly,* Volume vol 24, pp. 285-308.

Karasek, R. & Theorell, T., 1990. Stress, productivity and the reconstruction of working life. New York: Basic Books. Em: New York: Basic Books, pp. http://paei.wikidot.com/karasek-demand-control-model-of-job-stress.

Kasket, E., 2006. Death and the Doctor. *Existential Anaysis,* p. 17.1: January.

Kass, R. & Tinsley, H., 1979. Factor Analysis. *Journal of Leisure Research,* Volume 11, pp. 120-138.

Kearney, M. et al., 2009. Self-care of Physicians Caring for Patients at the End of Life "Being connected....A Key to My Survival. *JAMA,* pp. 301(11):1155-1164.

Keidel, G., 2002. Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice and Palliative Care,* pp. vol 19, nº 3; May-June.

Khader, K. J. S. S. A. J., 2010. Influence of nurses' characteristics and education on their attitudes towards death and dying: a review of literature. *International Journal of Nursing and Midwifery,* pp. vol 2(1), pp, 1-9, June.

Kim, S., Lee, Y., 2003. Korean nurses' attitudes to good and bad death, life-sustaining and advance directives treatment. *Nursing Ethics,* pp. 10 (6): 624-637.

King, N., 1994. The qualitative Research Interview. In: C. a. G. Symon, ed. *Qualitative Methods in Organizational Research.* London: Sage, p. 271.

Kings College London, 2012. Palliative Care MSc/PG dip/PG cert. *website Kings College London,* p. http://www.csi.kcl.ac.uk/files/PalliativeCare_final.pdf.

Kirchberg, T.M., Neimeyer, R.A., James, R.K., 1998. Beginning counselors' death concerns and empathic responses to client situations involving death and grief. *Death Studies,* pp. 22, 99-120.

Kirchberg, T.M., Neimeyer, R.A., 1991. Reactions of beginning counselors to situations involving death and dying. *Death Studies,* pp. 15, 603-10.

Kleiber, D. & Enzmann, D., 1990. *Burnout: 15 years of Research: an international bibliography.* Göttingen: Hogrefe.

Krefting, L., 1991. Rigor in qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy,* 45(3), pp. 214-222.

Kübler-Ross, E., 1970. *On Death and Dying.* s.l.:Tavistock Publications Limited.

Kübler-Ross, E., 1970. Reactions to the Seminar on Death and Dying. In: *On Death and Dying.* s.l.:Tavistock Publications Limited, pp. 218-239.

Kurz, J. & Hayes, E., 2006. End of Life Issues Action: Impact of Education. *International Journal of Nursing Education Scholarship,* pp. vol 3, issue 1, article 18.

Lafer, G., Moss, H., Kirtner, R. & Rees, V., 2003. *Solving the nursing shortage: Best and worst practises for recruiting, retaining and recouping of hospice nurses.,* Washington DC: American Federation of State, County, and Municipal Employees, AFL-CIO.

Lange, M., Thom, B. & Kline, N., 2008. Assessing Nurses' attitudes toward death and caring for dying patients in a comprehensive cancer centre. *Oncology Nursing Forum,* pp. vol 35, Nº 6.

Laroque, G., 1986. *Circulaire DGS/275/3D du 26 août 1986 relative à l'organisation des soins et à l'accompagnement des malades en phase terminale (dite "circulaire Laroque ")..* [Online]
Available at: http://www.usp-lamirandiere.com/laroque.htm
[Accessed 20 03 2012].

Larsson, I. E., Sahlsten, M. J., Segesten, K. & Plos, K. A., 2011. Patients' Perceptions of Nurses' Behaviour that influence patient participation in nursing care: a critical incident study. *Nursing Research and Practice,* Volume 2011, article ID 534060, 8 pages.

Lawton, J., 2000. *The Dying Process - Patients' experiences of palliative care.* pg 142 ed. London: Routledge.

Lazarus, R. & Folkman, S., 1984. The coping process: an alternative to traditional formulation.. Em: *Stress Appraisal and Coping.* New York: Springer Publishing Co., pp. 141-180.

Le Blanc, P. et al., 2007. Take Care! The evaluation of a Team-Based Burnout Intervention Program for Oncology Care Providers. *Journal of Applied Psychology,* pp. vol 92, No 1, 213-227.

Leiter, M., Gascón, S., Martinez-Jarreta, B., 2010. Making Sense of Work Life: A structural Model of Burnout. *Journal of Applied Social Psychology,* pp. 40, 1, pp 57-75.

Leiter, M., 1991. The Dream Denied: Professonal Burnout and the Constraints of Service Organizations. *Canadian Psychology,* pp. 32:547-561.

Leiter, M., Gascón, S. & Martinez-Jarreta, B., 2010. Making Sense of Work Life: A structural Model of Burnout. *Journal of Applied Social Psychology,* pp. 40, 1, pp 57-75.

Leiter, M. & Maslach, C., 1998. Burnout. *Enclyclopedia of Mental Health,* Volume 1, pp. 347-357.

Leiter, M. & Maslach, C., 1999. Six areas of worklife: a model of the organizational context of burnout. *Journal Health Hum Serv Adm,* pp. Spring; 21(4): 472-89.

Leiter, M. & Maslach, C., 2000. Burnout and Health. Em: T. R. &. J. s. A. Baum, ed. *Handbook of Health Psychology.* s.l.:Hillsdale, NJ: Lawrence Earlbaum, pp. 415-426.

Leiter, M. & Maslach, C., 2003. Areas of Worklife: a structured approach to organizational predictors of job burnout. In: *Research in Occupational Stress and Well-being.* s.l.:Emeral Group Publishing Limited, pp. vol 3 pp. 91-134.

Leiter, M. & Maslach, C., 2009. Nurse turnover: the mediating role of burnout. *Journal of Nursing Management,* pp. 17, 331-339.

Leiter, M. P. & Maslach, C., 2005. A mediation model of job burnout. Em: *Research companion to organizational health psychology.* Cheltenhan, UK: Edward Elgar, pp. 544-564.

Leloup, J.Y. Hennezel, M., 2008. *Ars Moriendi.* s.l., s.n., p. accessed on5/1/2012.

Leloup, J. & Hennezel, M., 2008. *Spiritual Reteat "Ars Moriendi".* Barcelona, s.n., p. accessed on 5/1/2012.

Limonero, J. et al., 2010. Competencia personal percebida y ansiedad ante la muerte en estudantes de enfermería. *Ansiedad y Estrés,* pp. 16(2-3), 177-188.

Lincoln, Y. & Guba, E., 1985. *Naturalistic Inquiry.* Beverly Hills, CA: Sage Publications.

Lissandre, S. et al., 2008. Facteurs associés au burnout chez les soignants en oncohématologie. *Oncologie,* pp. 10: 116-124.

Long, A., Grayson, L. & Boaz, A., 2006. Assessing the quality of knowledge in social care: exploring the potential of a set of generic standards. *British Journal of Social Work,* 36(2), pp. 207-226.

Lourenço Marques, A. et al., 2009. O desenvolvimento dos cuidados paliativos em Portugal. *Patient Care.*

Lowry, F., 1997. Does doctors' own fear of dying hinder palliative care?. *CMAJ,* pp. 157(3): 301-302.

Lu, C. J. & Shulman, S., 2008. Rigor and flexibility in computer-based qualitiative research: Introducing the coding analysis toolkit. *International Journal of Multiple Researcg Approahces,* 2(1), pp. 105-117.

Luquette, J., 2007. Stress, compassion fatigue and burnout: effective selfcare techniques for oncology nurses by Luquette, J. 1997. *Oncology Nursing Forum,* pp. vol 34, Nº 2.

Lynch, T. et al., 2010. Barriers to the Development of palliative care in Western Europe. *Palliative Medicine,* pp. 24(8) 812-819.

Mackenzie, C., Poulin, P. & Seidman-Carlson, R., 2006. A brief mindfulness-based stress reduction intervention for nurses and nurse aides. *Applied Nursing Research,* pp. 19, 105-109.

Mallory, J., 2003. The impact of a palliative care educational component on attitudes toward care of the dying in undergraduate nursing students. *Journal of Professional Nursing,* pp. Vol 19, Nº 5 (Sept-Octo), pp 305-312.

Mann, T., 1901. *Budenbrooks.* Berlin: S. Fischer Verlag.

Marques-Teixeira, J., 2002. Burnout ou a Síndrome de Exaustão. *Saúde Mental,* pp. IV(2) 8-19.

Marshall, M. N., 1996. Sampling for qualitative research. *Family Practice,* 13(6).

Martínez Garcia, M., Centeno Cortéz, C. & Sanz-Rubiales, A., 2009. Estudio sobre el Síndrome de Burnout en Profesionales de Enfermería de Cuidados Paliativos del País Vasco. *Rev Med Univ Navarra,* 53(1), pp. 3-8.

Maslach, C., 1976. Burned-out. *Human Behaviour,* pp. 16-22.

Maslach, C., 1978. The Client Role in Staff Burn-out. *Journal of Social Issues,* Volume vol 34 nº 4, p. 112.

Maslach, C., Jackson, S. & Leiter, M., 1986. Maslach Burnout Inventory 3rd Ed. In: *Evaluating Stress.* Palo Alto (CA): Consulting Psychologists Press, p. 192.

Maslach, C., Jackson, S. & Leiter, M., 1997. Maslach Burnout Inventory 3rd Ed. In: *Evaluating Stress.* London: The Scarecrow Press, p. 192.

Maslach, C. & Leiter, M., 1997. *The truth about burnout.* San Francisco: Jossey-Bass.

Maslach, C., Schaufeli, W. & Leiter, M., 2001. Job Burnout. *Annual Reviews Psychologu,* pp. 52:397-422.

Mason, M., 2010. Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Forum: Qualitative Social Research,* 11(3).

McIntyre, T., 1994. Stress e os Profissionais de Saúde: Os que tratam também sofrem. *Análise Psicológica,* pp. 2-3 (XII): 193-200.

McMullen, L., 2007. Oncology nursing and compassion fatigue: Caring until it hurts. Who is caring for the caregiver?. *Oncology nursing forum,* 34(2).

Mearns, D., Thorne, B., 1988. *Person-centred Counselling in Action.* London: SAGE Publications.

Medland, J., Howard-Ruben, J. & Whittaker, E., 2004. Fostering Psychosocial Wellness in Oncology Nurses: Addressing Burnout and Social Support in the Workplace. *Oncology Nursing Forum,* pp. vol 31, Nº 1.

Meier, D., Back, A. & Morrison, R., 2001. The inner life of physicians and care of the seriously ill. *JAMA,* pp. 2876(23): 3007-3014.

Meier, D. & Beresford, L., 2006. Preventing Burnout. *Journal of Palliative Medicine,* pp. vol 9, Nº 5.

Meier, D. & Beresford, L., 2008. The Palliative Care Team. *Journal of Palliative Medicine,* pp. vol 11, Nº 5.

Mercadier, C., 2002. *Le Travail Émotionnel des soignants à l'Hôpital. Le corps au Coeur de l'interaction soignant-soigné.* Paris: Editions Seli Arslan.

Mok, E., Lee, W. & Wong, F., 2002. The issues of death and dying:employing problem-based learning in nursing education. *Nurse Education Today,* pp. 22, 319-329.

Molina HealthCare and California Academy of Family Physicians, 2004. *"I hear you talking, but I don't understand you!" Medical jargon & clear communication,* California: Molina Healthcare - California Academy of Family Physicians.

Moriarty, J. et al., 2007. Promoting the use of diverse sources of evidence: evaluating progress in the provision of services for people with dementia and their carers. *Evidence and Policy,* 3(3), pp. 385-405.

Morita, T. et al., 2004. Emotional burden of nurses in palliative sedation therapy. *Palliative Medicine,* pp. 18:550-557.

Morse, J. M., 1994. Designing funded qualitative research. In: N. K. D. &. Y. S. Lincoln, ed. *Handbook of qualitative research.* Ca. Sage: Thousand Oaks, pp. 220-35.

Morse, J.M. & Singleton, J. 2001. Exploring the technical aspects of "fit" in qualitative research. *Qualitative Health Research, 11(6), pp.841-847.*

Nasrallah, S. M. M. G. S. M., 2009. Patient-Physican Boundaries in Palliative Care Training: A case study and discussion. *Journal of Palliative Medicine,* pp. vol 12, Nº 12.

Neimeyer, R., 1994. *Death Anxiety Handbook.* Washington: Taylor and Francis.

Neimeyer, R., Moser, R. & Witttkowski, J., 2003. Assessing attitude toward dying and death:Psychometric considerations. *Omega: Journal of Death and Dying,* pp. 47(1), 45-76.

Neimeyer, R. & Wittkowski, J. M. R., 2004. Psychological research on death attitudes: an overview and evaluation. *Death Studies.*

Neto, I., 2010. CDS: Por mais e melhores cuidados paliativos em Portugal. *CDS-PP - Grupo Parlamentar*, pp. http://www.cds.parlamento.pt/gp/index.php?option=com_content&view=article&id=769:cds-por-mais-e-melhores-cuidados-paliativos-em-portugal&catid=54:saude&Itemid=64.

Nunnally, J., 1978. *Psychometric theory.* New York: McGray Hill.

Odena, O., 2013. Using Software to tell a trustworthy convincing and useful story. *International Journal of Social Research Methodology,* 16(5), pp. 355-372.

Ordem dos Enfermeiros (Nurses Association of Portugal), 2010. *Dados Estatísticos 2000-2010.,* Lisbon: Accessed Oct. 27, 2011. http://www.ordemenfermeiros.pt/membros/Documents/OE%20Dados%20Estatísticos% 20%.

Ordem dos Enfermeiros, 2011. *Dados estatísticos 2000-2011,* Lisbon: Ordem dos Enfermeiros.

Pallant, J., 2007. *SPSS Survival Manual - A step by step guide to data analysis using SPSS version 15.* Berkshire, England: Open University Press.

Palliative Care Australia, 2008. Palliative and end of life care glossary of terms. Volume Edition 1.

Payne, N., 2001. Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing,* pp. 33(3), 396-405.

Payne, S., 1998. A comparative study of death anxiety in hospice and emergency nurses.. *Journal of Advanced Nursing,* pp. 28(4), 700-706.

Pearlman, L. & Saakvitne, K., 1995. Treating therapists with vicarious traumatization and secondary traumatic stress disorders. Em: *Compassion Fatigue: Coping with secondary traumatic stress disroder in those who treat the traumatized.* New York: Brunner-Routledge.

Pereira, J. et al., 2010. *The Champlain Region Palliative Sedation Therapy Clinical Practice Guidelines and Protocols,* Ontario: Champlain Palliative and End-of-Life-Network.

Pereira, S. M., 2011. Burnout in palliative care: A systematic review. *Nursing Ethics,* Volume 18(3), pp. 317-326.

Pereira, S. M., 2011. *PhD thesis on "Burnout em Cuidados Paliativos. Uma perspectiva bioética",* Porto: Universidade Católica Portuguesa.

Pereira, S. M., Fonseca, A. M. & Carvalho, A. S., 2012. Burnout in nurses working in Portuguese palliative care teams: a mixed methods study. *International Journal of Palliative Nursing,* 18(8).

Perlman, B. & Hartman, E., 1982. Burnout: summary and future research. *Human Relations,* pp. 35, 283-305.

Peteet, J., Meyer, F. & Miovic, M., 2011. Possibly Impossible Patients: Management of difficult Behavior in Oncology Outpatients. *Journal of Oncology Practice,* pp. Vol 7, Issue 4 pg 242-246.

Peters, L. et al., 2013. How death anxiety impacts nurses' caring for patients at the end of life: a review of literature. *The Open Nursing Journal,* Volume 7, pp. 14-21.

Piedmont, R., 1993. A longitudinal analysis of burnout in the health care setting: the role of personal dispositions. *Journal of Personality Assessment,* pp. 61(3), 457-473.

Pines, A., Aronson, E. & Kafry, D., 1981. *Burnout: From tedium to personal growth.* s.l.:New York: Free Press.

Pines, A. M., 2002. A Psychoanalytic-existential approach to burnout: demontrated in the cases of a nurse, a teacher , and a manager. *Psychotherapy: Theory/Research/Practice/Training,* 39(1), pp. 103-113.

Pines, A. M. & Aronson, E., 1988. Career Burnout: Causes and Cures. Em: New York: Free Press.

Podsakoff, P. M. & Organ, D. W., 1986. Self-Reports in Organizational Research: Problems and Prospects. *Journal of Management,* 12(4).

Pope, C. & Mays, N., 2006. Chapter 7. Em: *Qualitative research in health care.* Oxford: Blackwell Publishing, pp. pg 69-70.

Potter, P. & Deshields, T., 2010. Compassion fatigue and burnout: prevalence among oncology nurses. *Clinical Journal of Oncology Nursing,* pp. Vol 14, Number 5.

Powney, J. & Watts, M., 1987. *Interviewing in Educational Research.* London: Routledge & Kegan Paul.

Pronost, A. & Tap, P., 1996. La Prevention du burnout chez les infirmières et ses incidences sur les stratégies de coping.. *Psychol Française,* pp. 41(2): 165-172.

Pronost, A. & Tap, P., 1997. Usure professionelle et formation en soins palliatifs. *Les Cahiers Internationaux de Psychologie Sociale,* p. Mars.

QSR International, 2007. *NVivo8.* Southport, UK.: QSR International Pty Ltd.

Quattrin, R. et al., 2006. Level of Burnout Among Nurses Working in Oncology in an Italian Region. *Oncology Nursing Forum,* pp. vol 33, Nº 4.

Queirós, P., 2005. *Burnout no trabalho e conjugal em enfermeiros portugueses.* Coimbra: Edições Sinais Vitais.

Ramirez, A. et al., 1995. Burnout and psychiatric disorder among cancer clinicians. *British Journal of Cancer,* pp. 1263-1269.

Ramsay, K., Ramsay, J. & Main, D., 2007. Both group peer counselling and individual counselling reduce anxiety and depression and increase self-esteem and overall life satisfaction in palliative cancer care. *Counselling Psychology Quarterly,* 20(2), pp. 157-167.

Raphael, B., 1984. *The anatomy of bereavement: a handbook for the caring professions.* London: Routledge.

Rauch, P.K. Muriel, A.C., 2006. *Raising an emotionally healthy child when a parent is sick.* New York: McGraw-Hill.

Reis, M., 2011. Hoje vive-se muito tempo a pensar que não se vai morrer - Entrevista à Dra Isabel G.Neto. *Mind Source: http://www.ionline.pt/portugal/isabel-galrica-neto-hoje-vive-se-muito-tempo-pensar-nao-se-vai-morrer*, accessed 20/2/2011.

Rhodes-Kropf, J., Meier, D. & Adelmann, R., 2003. Interns learning to care for dying patients. *Journal of Palliative Medicine,* pp. vol 6, Nr 6.

Rice, R., 1984. Organizational work and the overall quality of life. *Applied Social Psychology Annual,* pp. 5, 155-178.

Ritchie, J., Lewis, J. & Gillian, E., 2003. Designing and selecting samples. In: J. R. &. J. Lewis, ed. *Qualitative Research Practice. A guide for social science students and researchers.* CA: Sage: Thousand Oaks, pp. 77-108.

RNCCI-Rede Nacional de Cuidados Continuados Integrados, 2011. *Cuidados Paliativos Portugal,* s.l.: http://www.rncci.min-saude.pt/SiteCollectionDocuments/CuidadosPaliativosPortugal-evolucao.pdf.

Roberts, L. & Dyer, A., 2004. Caring For Difficult Patients. Em: *Concise Guide to Ethics in Mental Health Care.* Arlington: American Psychiatric Publishing, p. chapter 10.

Robson, C., 2002. *Real World Research.* 2nd ed. Oxford: Blackwell Publishing.

Rogers, 1951. *Client Centred Therapy.* London: Constable and Robinson Ltd.

Rogers, 1961. *On Becoming a Person,* Boston: Houghton Mifflin.

Rogers, C., 1973. *Encounter Groups.* s.l.:Penguin Books Ltd.

Rogers, C., 1980. *A way of being.* New York: Houghton Miffin Company.

Rogers, C. R., 1958. The Characteristics of a Helping Relationship. *Personnel and Guidance Journal,* pp. Journal 37, nº 1 pg 6-16.

Román, E., Ezquerro, O. & Sorribes, E., 2001. Nurses' attitudes to terminally ill patients. *Journal of Advanced Nursing,* pp. 34(3), 338-345.

Rosenfeld, B., Krivo, S., Breitbart, W. & Chochinov, H., 2000. Suicide, assisted suicide, and euthanasia in the terminally ill. In: *Handbook of Psychiatry in Palliative Medicine.* s.l.:Oxford University Press, pp. 51-62.

Rushton, C., Sellers, D., Heller, K., Spring, B.,Dossey, B., Halifax, J., 2009. Impact of a contemplative end-of-life training program: Being with dying. *Palliative and Supportive Care,* pp. 7, 405-414.

Ruszniewski, M. & Zivkovic, L., 1999. Difficulties faced by hospital palliative care teams. *European Journal of Palliative Care,* p. 6(1).

Salmela-Aro, K., Näätänen, P. & Nurmi, J., 2004. The role of work related personal projects during two burnout interventions: a longitudinal study. *Work & Stress,* pp. vol 18, Nº 3, 208-230.

SA-MA-SA, 2012. *SA-MA-SA Education Midi-Pyrénées.* [Online]
Available at: http://www.samasa-education-mp.fr/
[Accessed 4 1 2012].

Sartorius, N., 2010. *The ICD-10 Classification of Mental and Behavioural Disorders.* s.l.:World Health Organization.

Sauter, S., Hurrell, J. & Cooper, C., 1989. *Job control and Worker Health.* New York: Wiley.

Schaufeli, W. & Buunk, B., 1996. Professional Burnout. In: J. Schabracq, M. Winnubst & C. Cooper, eds. *Handbook of Work and Health Psychology.* s.l.:s.n., p. 386.

Schaufeli, W. & Enzmann, D., 1998. *The Burnout Companion to Study and Practice: A critical analysis.* London: Taylor & Francis.

Schaufeli, W., Enzmann, D. & Girault, N., 1993. Measurement of Burnout: A Review. In: Schaufeli, Marek & Maslach, eds. *Professional Burnout: Recent Developments in theory and Research.* Philadelphia: Taylor & Francis, p. 207.

Schaufeli, W., Maslach, C. & Marek, C., 1993. Historical and conceptual development of burnout. Em: *Professional burnout: Recent developments in theory and research.* Washington, Dc: Taylor & Francis.

Schilling, J., 2006. On the pragmatics of qualitative assessment: Designing the process for content analysis. *European Journal of Psychological Assessment,* 22(1), pp. 28-37.

Schwartz, M., 1997. *Morrie In His Own Words.* New York: Dell Publishing.

Schwartz, M. & Will, G., 1953. Low morale and mutual withdrawal on a hospital ward. *Psychiatry,* pp. 16, 337-53.

Shadish, W. R., Cook, T. D. & Campbell, D. T., 2001. *Experimental and quasi-experimental designs for generalized causal inference.* 2nd ed. New York: Centgage Learning.

Shenton, A., 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information,* Volume 22, pp. 63-75.

Shields, L. & Pearn, J., 2007. Inducements for medical and health research: issues for the profession of nursing. *Journal of Clinical Nursing,* pp. 1196-1200.

Shirom, A., 1989. Burnout in Work Organizations.. *International Review of Industrial and Organizational Psychology,* pp. 25-48.

Shirom, A., Nirel, N. & Vinokur, A., 2006. Overload, Autonomy and burnout as Predictors of Physicians' Quality of Care. *Journal of Occupational Health Psychology,* pp. vol 11, Nº 4, 328-342.

Siegal, D., 2001. Towards an interpersonal neurobiology of the developing mind: attachment relationship "mindsight" and neural integration. *Infant Mental Health Journal,* pp. vol 22(1-2), 67-94- Michigan Association for Infant Mental Health.

Siegrist, J., 1996. Adverse health effects of high-effort/low-reward conditions.. *Journal of Occupational Health Psychology,* pp. 1, 27-41.

Siegrist, J., Siegrist, K. & Weber, I., 1986. Sociological concepts in the etiology of chronic disease: the case of ischemic heasrt disease. *Social Science and Medicine,* pp. 22, 247-253.

Silberfarb, P. & Levine, P., 1980. Psychosocial aspects of neoplastic disease III group support for the oncology nurse. *General Hospital Psychiatry,* pp. 3, 192.

Simon, S. & Higginson, I., 2009. Evaluation of hospital palliative care teams: strengths and weaknesses of the before-after study design and strategies to improve it.. *Palliative Medicine,* Volume 23, pp. 23-28.

Simpson, C., 2004. When hope makes us vulnerable: A discussion of patient-healthcare provider interactions in the context of hope. *Bioethics,* 18(5), pp. 428-477.

Sin, C. H., 2007. Using Software to open up the 'Black Box' of qualitative data analysis in evaluations. *Evaluation,* 13(1), pp. 110-120.

Smith-Cumberland, T., 2006. The evaluation of two death education programs for EMTs using the theory of planned behaviour. *Death Studies,* Volume 30, pp. 637-647.

Soares, J., 2010. *Exaustão Emocional dos cuidadores de doentes oncológicos-Eficácia de uma intervenção de grupo,* Porto: Universidade do Porto, Faculdade de Psicologia e ciências de educação.

Spratt, C., Walker, R. & Robinson, B., 2004. Module A5 - Mixed Research Methods. In: *PREST - Practitioner Research and Evaluation Skills Training in Open and Distance Learning.* s.l.:Commonwealth of Learning.

St Christopher's Hospice, 2012. *St Christopher's Hospice.* [Online]
Available at: http://www.stchristophers.org.uk/about/facts
[Accessed 20 March 2012].

Stange, K., Crabtree, B. F. & Miller, W., 2006. Publishing Multimethod Research. *Annals of Family Medicine,* 4(4).

Steginga, S. et al., 2005. Impact of an intensive Nursing Education Course on Nurses' Knowledge, Confidence, Attitudes, and Perceived Skills in the Care. *Oncol. Nursing Forum,* pp. 32(2): 375-381.

Stephan, W. G., 2006. Bridging the Researcher-Practitioner Divide in Intergroup Relations. *Journal of Social Issues,* 62(3), pp. 597-605.

Stevens, K. & Ledbetter, C., 2000. Basis of evidence-based practice. Part 1: the nature of the evidence. *Semin Perioperative Nursing,* 47(1), pp. 91-97.

Streiner, D. L. & Norman, G. R., 2008. Chapter 3 to 5. In: *Health Measurement Scales.* 4th ed. Oxford: Oxford University Press.

Streubert, H. J. & Carpenter, D., 1999. *Qualitative research in nursing:Advancing the humanistic imperative.* 2nd ed. Philadelphia: Lippincott.

Sulmasy, D., 2002. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist,* pp. 42(3): 24-33.

Sundin-Huard, D. & Fahy, K., 1999. Moral distress, advocacy and burnout:Theorising the relationships. *International Journal of Nursing Practice,* pp. 5:8-13.

Sun, F., Long, A., Yi Huang, X. & Chiang, C., 2011. A quasi-experimental investigation into the efficacy of a suicide education programme for second-year student nurses in Taiwan. *Educational issues in clinical nursing,* Volume 20, pp. 837-846.

Tabachnick, B. & Fidell, L., 1996. *Using multivariate statistics (3rd edition).* New York: Harper & Row.

The National Council for Palliative Care, 2011. *Commissioning End of Life Care.* [Online]
Available at: http://www.ncpc.org.uk/sites/default/files/AandE.pdf
[Acedido em 1 11 2013].

Thomas, R. & Wilson, J., 2004. Issues and controversies in the understanding and diagnosis of compassion fatigue, vicarious traumatization and secondary traumatic stress disorder.. *International Journal of Emergency Mental hHealth,* 6(2), pp. 81-92.

Thorndike, E., McCall, W. & Chapman, J., 1916. Ventilation in relation to mental work. In: *Teachers College Contributions to Education.* s.l.:s.n.

Todaro-Francheschi, V., 2011. Changing the face of death: a pedagogic intervention. *Journal of Professional Nursing,* pp. vol 27, Nº 5 (Sept-Oct), pp. 315-319.

Tomer, A. & Eliason, G., 1996. Toward a comprehensive model of death anxiety. *Death Studies,* pp. 20: 343-365.

Tomer, A. & Eliason, G., 2000. Attitudes about life and death:Toward a comprehensive model of death anxiety. In: A. Tomer, ed. *Death attitudes and the older adult: theories, concepts and applications.* Philadelphia: Taylor and Francis.

Tomer, A. & Eliason, G., 2005. Life regrets and death atitudes in college students. *Omega - Journal of Death and Dying,* Volume 51, pp. 173-195.

Toscani, F., 2002. Palliative care in Italy: accident or miracle?. *Palliative Medicine,* Volume 16, pp. 177-178.

Trochim, W., 1995. *The concept system.* New York: Thaca.

Truog, R., Berde, C., Mitchell, C. & Grier, H., 1992. Barbiturates in the care of the terminally ill. *New England Journal of Medicine,* 327(23), pp. 1678-1682.

Twycross, R., 2005. Death without Suffering?. *European Journal of Palliative Care,* p. 12(2) Supplement.

Unidade de Missão para os Cuidados Continuados Integrados, 2010. *Estratégia para o desenvolvimento do programa nacional de cuidados paliativos 2011-2013,* Lisboa: Serviço Nacional de Saúde.

University of Southern California, 2013. *Organizing your social sciences research paper.* [Online]
Available at: http://libguides.usc.edu/print_content.php?pid=83009&sid=615851
[Acedido em 20 11 2013].

Vachon, M., 1987. *Ocupational stress in the Care of the Critically ill, the Dying and the Bereaved.* New York: Hemisphere.

Vachon, M., 1997. Recent Research into staff stress in palliative care. *European Journal of Palliative Care,* pp. 4(3): 99-103.

Vachon, M., 2000. Burnout and symptoms of stress in staff working in Palliative Care. Em: M. B. Harvey M. Chochinov, ed. *Handbook of psychiatry in palliative care.* s.l.:Oxford University Press.

Vachon, M., 2011. *Four decades of selected research in hospice/palliative care: have the stressors changed?.* New York: Oxford University Press.

Vachon, M., Lyall, W. & Freeman, S., 1977. Measurement and management of stress in health professionals working with advanced cancer patients. *Death Studies,* pp. vol 1, Issue 4.

Valent, P., 2002. Diagnosis and treatment of helper stresses, traumas and illnesses. Em: C. Figley, ed. *Treating Compassion Fatigue.* New York: Brunner-Routledge, pp. 17-37.

Van Staa, A., Visser, A. & Van der Zouwe, N., 2000. Care for caregivers: experiences and evaluation of interventions for a palliative care team. *Patient Educ Couns,* pp. 41: 93-105.

Walton, A. L. & Alvarez, M., 2010. Imagine: Compassion Fatigue Training for Nurses. *Clinical Journal of Oncology Nursing,* pp. vol 14, Nº 4 - Heart of Oncology Nursing.

Wasner, M., Longaker, C., Fegg, M. & Borasio, G., 2005. Effects of a spiritual care training for palliative care professionals. *Palliative Medicine,* pp. 19(2): 99-104.

Wass, H., 2004. Perspective on the current state of death education. *Death Studies,* pp. 28:289-308.

Webb, R. & Vulliamy, G., 2007. Changing Classroom practice at key stage 2: the impact of new labour's mnatonal strategies. *Oxford Review of Eduation,* 33(5), pp. 561-580.

Weiniger, R. & Kearney, M., 2011. Revisiting empathic engagement: countering compassion fatigue with "Exquisite Empathy". In: *Caregiver Stress and Staff Support in Illness, Dying and Bereavement.* Oxford: Oxford University Press, pp. 49-61.

Weitzman, E., 2000. Software and Qualitative research. Em: *Handbook of Qualitative Research.* 2nd ed. Thousand Oaks, CA.: Sage Publications, pp. 803-820.

Wessel, E. & Rutledge, D., 2005. Home care and hospice nurses' attitudes toward death and caring for the dying. *Am. Hosp. Palliative Care,* pp. 7(4) 212-218.

Whippen D.A., Canellos, G.P., 1991. Burnout syndrome iin the practice of oncology: results of a random survey of 1000 oncologists. *Journal of clinical Oncology.*

Williams, C. M., Wilson, C. & Olsen, C., 2005. Death and Medical Education: Student Voices. *Journal of Palliative Medicine,* pp. vol 8, nº 2.

Wong, P., Reker, G. & Gesser, G., 1994. Death Attitude Profile – Revised: A multidimensional measure of attitudes toward death. In: R. Neimeyer, ed. *Death anxiety handbook: Research instrumentation and application .* Washington DC: Taylor and Francis, pp. 121-148.

World Health Organization, 2002. *World Health Organization.* [Online]
Available at: http://www.who.int/cancer/palliative/definition/en/
[Accessed 06 June 2011].

Wowchuk, S., McClement, S. & Bond, J., 2007. The challenge of providing palliative care in the nursing home, part II: internal factors. *International J. Palliative Nursing,* pp. 13(7): 345-350.

Yalom, I. D., 1995. *The Theory and Practice of Group Psychotherapy.* 4th ed. New York: Basic Books.

Yang, G. M., Ewing, G. & Booth, S., 2011. What is the role of specialist palliative care in an acute hospital setting? A qualitative study exploring views of patients and carers. *Palliative Medicine,* Volume 26(8), pp. 1011-1017.

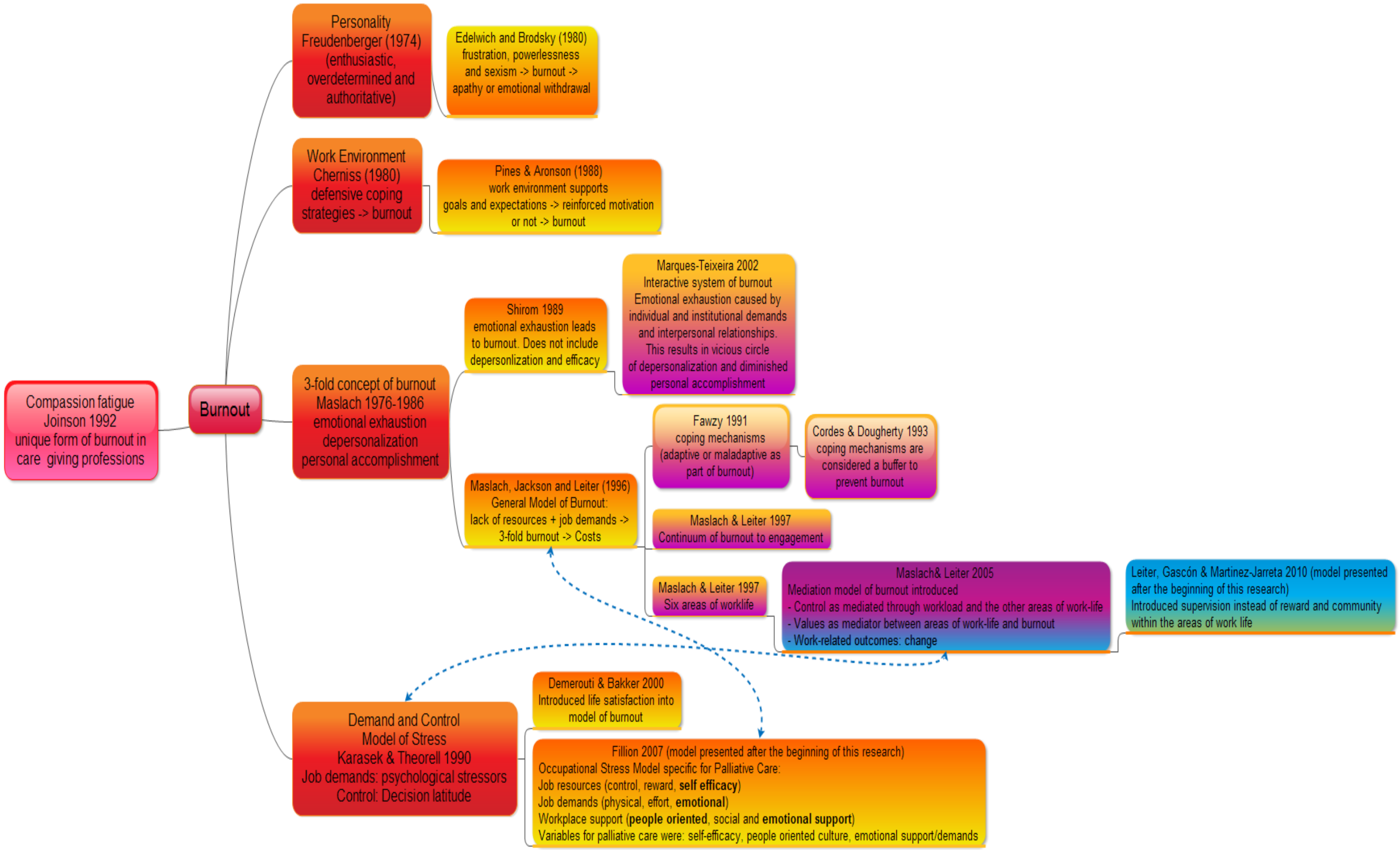
Youngson, R., 2011. Compassion in healthcare - the missing dimension of healthcare reform?. In: *Caregiver Stress and Staff Support in Illness, dying and Bereavement.* New York: Oxford University Press, p. chapter 3.

Zucco, F., 2010. *Hospice (and Palliative Care Network in Italy) an unpredictable growth.* Milan, Garbagnate MilaneseHospital Trustee.

Zundel, M., 1979. *À l'ecoute du silence.* s.l.:Tequi.

APPENDICES

APPENDIX 1 - SYNTHESIS OF THEORIES AND MODELS OF BURNOUT


Compassion fatigue
Joinson 1992
unique form of burnout in care giving professions
Burnout
Personality
Freudenberger (1974)
(enthusiastic, overdetermined and authoritative)
Edelwich and Brodsky (1980)
frustration, powerlessness and sexism -> burnout -> apathy or emotional withdrawal
Work Environment
Cherniss (1980)
defensive coping strategies -> burnout
Pines & Aronson (1988)
work environment supports goals and expectations -> reinforced motivation or not -> burnout
3-fold concept of burnout
Maslach 1976-1986
emotional exhaustion
depersonalization
personal accomplishment
Shirom 1989
emotional exhaustion leads to burnout. Does not include depersonlization and efficacy
Marques-Teixeira 2002
Interactive system of burnout
Emotional exhaustion caused by individual and institutional demands and interpersonal relationships.
This results in vicious circle of depersonalization and diminished personal accomplishment
Maslach, Jackson and Leiter (1996)
General Model of Burnout:
lack of resources + job demands -> 3-fold burnout -> Costs
Fawzy 1991
coping mechanisms (adaptive or maladaptive as part of burnout)
Cordes & Dougherty 1993
coping mechanisms are considered a buffer to prevent burnout
Maslach & Leiter 1997
Continuum of burnout to engagement
Maslach & Leiter 1997
Six areas of worklife
Maslach& Leiter 2005
Mediation model of burnout introduced
- Control as mediated through workload and the other areas of work-life
- Values as mediator between areas of work-life and burnout
- Work-related outcomes: change
Leiter, Gascón & Martinez-Jarreta 2010 (model presented after the beginning of this research)
Introduced supervision instead of reward and community within the areas of work life
Demand and Control
Model of Stress
Karasek & Theorell 1990
Job demands: psychological stressors
Control: Decision latitude
Demerouti & Bakker 2000
Introduced life satisfaction into model of burnout
Fillion 2007 (model presented after the beginning of this research)
Occupational Stress Model specific for Palliative Care:
Job resources (control, reward, self efficacy)
Job demands (physical, effort, emotional)
Workplace support (people oriented, social and emotional support)
Variables for palliative care were: self-efficacy, people oriented culture, emotional support/demands

APPENDIX 2 -IDENTIFICATION SHEET FOR CONTROL GROUP 4 MONTHS LATER

Date: ____/____/____ id nº________

I work with patients with a terminal condition in a palliative care unit: ___
I work with patients with a terminal condition out of a palliative care unit ___
Unit where I work at present:___________________
Unit where I worked when I filled in the 1st questionnaire __________
Date of Birth:_______________ Age:__________
Gender: F_____ M_____

Academic qualifications:
___ 4th grade
___ 6th grade
___ 9th grade
___12th grade
___ Honours degree: ____________________________________
___ Masters or post-graduate in:__________________________
___ PhD in: ___________________________________

Nationality:_________________________
Profession:
___ nursing aide
___ nurse
___ Doctor
___ Psychologist
___ Physiotherapist
___ Volunteer
___ Other:_________________

You live:
____ alone
____ with your parents and/or other members of your family
____ with your partner
____ with your partner and child/children
____ with your children
____ with children who are dependent on you
____ with friends
____ other:___________________________________

Contacts (optional)

E-mail:________________ ; Telephone: ______________

APPENDIX 3 - LETTER TO THE CONTROL GROUP

Dear Colleague,

AMARA is carrying ou a scientific research project, supported by the Calouste Gulbenkian Foundation. The purpose is to evaluate and demonstrate the importance of a training intervention, involving the psycho-existential approach to life and death for people who care for patients with a terminal condition, in order for them to cope with burnout and consequently improve patient care.

I would like to invite you to participate in the control group (group with no training), by filling in three questionnaires, which will be used in the project. The questionnaires refer specifically to:

- Evaluation of levels of “burnout”
- Evaluation of levels of helping relationship skills
- Evaluation of levels of inner well-being

The questionnaire will be passed out again in 4 months time.

You are also asked to answer some question on demographic data, and academic/professional training. I would like to thank you in advance for your patience and the time you have given to fill in the questionnaires, without which, this project would not have been possible.

This study was planed to guarantee the respect for all ethical and deontological norms with regard to secrecy and confidentiality of your answers in the processing and final presentation of data. Please be sincere when answering the questions, even if your answer does not please you. It is important for the validity of the research not to have “socially correct” answers. May I remind you that the purpose of the research has nothing to do with personal evaluation.

You are given the option to register your e-mail and telephone number for us to be able to contact you in case there are any faults in filling in the data, because filling in all the questions (not leaving any in white) is fundamental for the final result of the research. All the e-mails and phone numbers are kept confidential and will not be used for any other purpose other than being contacted by the researcher.

As a participant, you should know that:

The answers are completely anonymous and should you leave me your e-mail and telephone number, these will be kept in a file separate from the data.

For any further questions regarding this study, or if you have doubts or worries after filling in the questionnaire, please contact me.

Please take note of your id nº, because you will need to use the same id in 4 month’s time which you fill in the questionnaires again. Thank you very much

e-mail: carol.costeloe@amara-project.org; telephone 916162911.

Thank you very much advance.
Carol Gouveia e Melo
Dept of Research - AMARA

APPENDIX 4 - LETTER TO THE CONTROL GROUP 4 MONTHS AFTER THE 1ST QUESTIONNAIRE

Dear Colleague,

Some months previously, you were kind enough to accept to participate in the control group of a scientific research project carried out by AMARA, and supported by the Calouste Gulbenkian Foundation. The purpose of this research was to evaluate and demonstrate the importance of a training intervention, involving the psycho-existential approach to life and death for people who care for patients with a terminal condition, in order for them to cope with burnout and consequently improve patient care. The questionnaires you filled in were:

- Evaluation of levels of “burnout”
- Evaluation of levels of helping relationship skills
- Evalutaion of levels of inner well-being

The time has come now to fill in the same questionnaires again, in order to evaluate whether there is a difference between the group that underwent the intervention and the group that did not.

This study was planed to guarantee the respect for all ethical and deontological norms with regard to secrecy and confidentiality of your answers in the processing and final presentation of data. Please be sincere when answering the questions, even if your answer does not please you. It is important for the validity of the research not to have “socially correct” answers. May I remind you that the purpose of the research has nothing to do with personal evaluation.

You are given the option to register your e-mail and telephone number for us to be able to contact you in case there are any faults in filling in the data, because filling in all the questions (not leaving any in white) is fundamental for the final result of the research. All the e-mails and phone numbers are kept confidential and will not be used for any other purpose other than being contacted by the researcher.

As a participant, you should know that:

Yours answers are completely anonymous, and if you chose to leave me your e-mail and telephone number, these will be kept in a file separate from your data.

For any further questions regarding this study, or if you have doubts or worries after filling in the questionnaire, please contact me; Please do not forget to fill in which floor you are working on (and/or were working on when you filled in the first questionnaire) and your birth date, because this is what will allow me to link the second questionnaire to the first.

e-mail: carolgouveiamelo@amara.pt telefone 916162911.

Thank you very much in advance.

Carol Gouveia e Melo

Dept of Research - AMARA

APPENDIX 5 - LETTER TO PARTICIPANTS BEFORE THE TRAINING

Dear Colleague,

AMARA is carrying out a scientific research project, supported by tye Calouste Gulbenkian Foundation. The purpose of this research was to evaluate and demonstrate the importance of a training intervention, involving the psycho-existential approach to life and death for people who care for patients with a terminal condition, in order for them to cope with burnout and consequently improve patient care.

I would like to invite you to participate by filling in three questionnaires which will be used in the project. The questionnaires refer specifically to:

- Evaluation of levels of “burnout”
- Evaluation of levels of helping relationship skills
- Evalutaion of levels of inner well-being

These questionnaire together with some qualitative questions will be presented to you again in 4 months time, to evaluate if there dhas been any change or not. You are also asked to answer some question on demographic data, and academic/professional training. I would like to thank you in advance for your patience and the time you have given to fill in the questionnaires, without which, this project would not have been possible.

This study was planed to guarantee the respect for all ethical and deontological norms with regard to secrecy and confidentiality of your answers in the processing and final presentation of data. Please be sincere when answering the questions, even if your answer does not please you. It is important for the validity of the research not to have “socially correct” answers. May I remind you that the purpose of the research has nothing to do with personal evaluation

You are given the option to register your e-mail and telephone number for us to be able to contact you in case there are any faults in filling in the data, because filling in all the questions (not leaving any in white) is fundamental for the final result of the research. All the e-mails and phone numbers are kept confidential and will not be used for any other purpose other than being contacted by the researcher.

As a participant, you should know that:

The answers are completely anonymous and should you chose to leave me your e-mail and telephone number, these will be kept in a file separate from the data.

For any further questions regarding this study, or if you have doubts or worries after filling in the questionnaire, please contact me.

Please take note of your id nº, because you will need to use the same id in 4 months time when you fill in the questionnaires again. Thank you very much..

e-mail: carol.costeloe@amara-project.org ; telephone 916162911.

Thank you very much in advance
Carol Gouveia e Melo
Dept of Research - AMARA

APPENDIX 6 - IDENTIFICATION SHEET FOR FIRST QUESTIONNAIRE

Date: ____/____/____ Nº id________

I work with patients with a terminal condition in a palliative care unit: ___
I work with patients with a terminal condition in other units with no palliative care ___
For how long?_______________
Name of institution where you work:___________________
Date of Birth:_______________ Age:__________
Gender: F_____ M_____

Academic qualifications:
___ 4th grade
___ 6th grade
___ 9th grade
___12th grade
___ Honours degree: ___________________________________
___ Masters or post-graduate in:_________________________
___ PhD in: __________________________________

Nationality:________________________

Profession:
___ nursing aide
___ nurse
___ Doctor
___ Psychologist
___ Physiotherapist
___ Volunteer
___ Other:_________________

You live:
____ alone
____ with your parents and/or other members of your family
____ with your partner
____ with your partner and child/children
____ with your children
____ with children who are dependent on you
____ with friends
____ other:__________________________________

Contacts (optional)
E-mail:_______________ ; Telephone: _____________

APPENDIX 7 - IDENTIFICATION SHEET FOR SECOND QUESTIONNAIRE (EXPERIMENTAL GROUP)

Date: ____/____/____ Nº id________

Name of institution where you work:___________________
Date of birth:_______________
Gender: F_____ M_____
Contacts (optional): E-mail:________________ ; Telephone: _____________

Dear Colleague

Four months have gone by since the intervention with AMARA, for the research project funded by the Calouste Gulbenkian Foundation and we now ask your collaboration in order to evaluate the impact of the intervention. For this, we present you with the same questionnaires as before the intervention, with one more column, which is to evaluate your opinion TODAY, of how you felt BEFORE the intervention.
We asks for this information in order to understand whether the intervention also changed your criteria of rigour or evaluation. For example, whereas four months ago you may have answered 6 to the question “I feel I am genuine with them”, today you may have a different opinon. In other words, you may think that you are more genuine today than you were four months ago, but if four months ago you wrote 6, then this improvement cannot be expressed. Therefore, if for example you now write 3, this would mean that today you think your were level before the intervention was 3.

Apart from the questionnaires, I would also like you to answer in your own words, the following questions:

- What was the most important thing you learnt in this intervention?
- What was the main help that this intervention brought you?
- What did you value (or not) in the intervention (in terms of content, structure, teaching methodology, liberty to express feelings etc) ?

In what way did the intervention serve to improve (or not) (please be specific):
- Your relationship with the patient
- Your relationship with the family
- Your relationship with work colleagues
- Your efficiency at work
- Your self-knowledge
- Your internal congruence
- Your daily life and feelings of well-being

In your opinion, how could the intervention be improved?

In your opinoin, would there be any benefit in follow-up workshops? If so, which themes would you like to approach:

- Comunication dificulties with the patient and family
- Communication difficulties within the team
- Spiritual support
- Health Care workers’ emotional responsein relation to the patient’s body (smells, different types of touches and looks, “symbolic contagions” etc.

- Meaning in life
- Non directive group encounters
- Any other theme you would like to suggest
- Any other comment you would like to add (optional).

If possible, please send this information in word by e-mail to: carolgouveiamelo@amara.pt together with your id nº. If this is not possible, you may hand it in together with the questionnaire.

Thank you for all your help!

Carol Gouveia e Melo

APPENDIX 8 - QUESTIONNAIRE TO ASSESS BURNOUT (BEFORE AND AFTER TRAINING)

QUESTIONNAIRE ON BURNOUT ID Nº ____

Following is a list of several statements related to burnout in health care workers. They are to evaluate your risk of burnout in relaton to your work.

Consider ech statement with respect to yourself in general.

Opn the right hand side of the page, put a cross for each statement from 1 to 6 where:

1 = I disagree completely and 6 = I agree completely

This questionnaire is anonymous. It is important for this project that you answer all questions sincerely, and avoiding “socially desirable” answers.

Thank you for the time you have given to me.

I DISAGREE COMPLETELY I AGREE COMPLETELY

1	I feel emotionally drained by my work.	1	2	3	4	5	6
2	I feel that I treat many people impersonally, as if they were objects.	1	2	3	4	5	6
3	I resolve other people’s problems efficiently.	1	2	3	4	5	6
4	I would be incapable of coping with my work if I considered my patients as unique individuals.	1	2	3	4	5	6
5	I can easily understand what other people are experiencing.	1	2	3	4	5	6
6	I feel tired when I get up in the morning and have to face another day of work.	1	2	3	4	5	6
7	I have become more insensitive to people since I have this job.	1	2	3	4	5	6
8	I feel frustrated by my work.	1	2	3	4	5	6
9	I feel fulfilled at work because I manage to find time to just “be” with the patient or their family.	1	2	3	4	5	6
10	I feel helpless when faced with the patient’s fragility.	1	2	3	4	5	6
11	My work allows me to value life more.	1	2	3	4	5	6
12	I am afraid this job will make me become emotionally hard.	1	2	3	4	5	6
13	I am frustrated because I cannot find the time to have a	1	2	3	4	5	6

	quality relationship with the patient.						
14	It is easy for me to create a relaxed atmosphere with other people.	1	2	3	4	5	6
15	I feel worn out.	1	2	3	4	5	6
16	I do not pay real attention to what happens to other people.	1	2	3	4	5	6
17	I feel fulfilled when I work in close collaboration with others.	1	2	3	4	5	6
18	Working every day with people is a real burden for me.	1	2	3	4	5	6
19	I have accomplished many useful things in this work.	1	2	3	4	5	6
20	I have no strength left at the end of a day's work.	1	2	3	4	5	6
21	Dealing psychologically with terminally ill patients makes me feel insecure and anxious.	1	2	3	4	5	6
22	I feel that what I do makes a difference.	1	2	3	4	5	6
23	I feel that I work too hard in my profession.	1	2	3	4	5	6
24	I don't really care what happens to my patients.	1	2	3	4	5	6
25	I am emotionally disturbed by the death of so many patients.	1	2	3	4	5	6
26	At work, I deal with emotional problems very calmly.	1	2	3	4	5	6
27	I cannot afford to answer to the individual needs of my patients.	1	2	3	4	5	6
28	The relationship with the patient's family wears me out.	1	2	3	4	5	6
29	I feel that other people have realistic expectations regarding my working performance.	1	2	3	4	5	6
30	I give more importance to the technical part of my work than to the human part.	1	2	3	4	5	6
31	Working directly with people causes me a lot of stress.	1	2	3	4	5	6
32	I have a positive influence on the people I coordinate at work.	1	2	3	4	5	6
33	I have moments of sharing with the patients, with no need to hide my feelings.	1	2	3	4	5	6
34	I give a lot of importance to treating the illness, but do not have patience for the psychological and spiritual caring of the patient.	1	2	3	4	5	6

35	I feel stressed due to lack of debate and support within the team, with regard to our difficulties.	1	2	3	4	5	6
36	I feel energetic.	1	2	3	4	5	6
37	I feel that other people censor me because of their own problems.	1	2	3	4	5	6
38	I ask myself many times if I could have “done more” and this makes me feel anxious.	1	2	3	4	5	6
39	I manage to find time in my work to talk to patients and to help them find meaning in their lives.	1	2	3	4	5	6
40	I often contribute towards giving my patients quality of life, comfort and dignity at the end of their life.	1	2	3	4	5	6

APPENDIX 9 - AUTHORIZATION TO USE THE MASLACH BURNOUT INVENTORY (MBI)

Re: MGWeb: Comment from carol gouveia melo (Product Question)

---

info@mindgarden.com <info@mindgarden.com> 25 February 2011 19:44

To: carolgouveiamelo@gmail.com

Hi Carol,
You are welcome to use just some of the MBI questions, with proper copyright attribution of those items.

Best,
Valorie Keller
Mind Garden, Inc.

Quoting carolgouveiamelo@gmail.com:

Name: carol gouveia melo
Email address: carolgouveiamelo@gmail.com
Phone number: 00351962730796
Company/Institution: university of kent
Country: portugal
Order/Invoice number:
Purchase Order number:
Topic of comment: Product Question

Comment:
Dear Sirs
I am doing a PhD at the University of Kent, but I live in Portugal. I am constructing a questionnaire in Portuguese specifically to measure levels of burnout in health care workers who care for the dying in Portugal. I would like to use some of the questions in the MBI for human services. Can I buy a Portuguese version of your inventory and use some of the questions to create a questionnaire that will also have other questions more directed to the area I am studying? Thank you for your cooperation.

How did you hear about us? ISPA Instituto Universitário

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 25 February 2011 23:19

To: info@mindgarden.com

Dear Valorie

The scale I am constructing has 40 questions, 21 out of which would be from the MBI. Is that still alright? (It is not just a few!) Of course my thesis and any article I write would say where the questions came from. I would be quite happy to buy the inventory if that is required.

Thank you

Carol

---

info@mindgarden.com <info@mindgarden.com> 25 February 2011 23:52

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

Hi Carol,

Yes, a license purchase is required. We do not yet have the MBI translations listed on our website so you could use an Order Form to order the license.

Here is a link to the order form -- if you choose the MS Word form you can type into it and email it to us as an attachment.
http://www.mindgarden.com/ordering.htm#orderformna

The product code is not important as long as you indicate MBI (which form? GS or HSS ?) PDF and the quantity.

Here is a link to the MBI page where you will see license prices.
http://www.mindgarden.com/products/mbi.htm

Hope this helps.

Best,
Valorie

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 26 February 2011 00:17

To: info@mindgarden.com

Thank you. I will send the order tomorrow.

Best wishes

Carol

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 28 February 2011 11:15

To: info@mindgarden.com

Dear Valorie

Here goes my order. Could you give me a phone nº I can ring to give you the visa details.? I would rather do this over the phone.

I gather I have made the order correctly?

Thank you

Carol Gouveia e Melo

---

info@mindgarden.com <info@mindgarden.com> 28 February 2011 22:00

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

Hello Carol,
Our phone is 650-322-6300. I will be here until about 4:30 today, Pacific Daylight Time in California.
Best,
Valorie
Mind Garden, Inc

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 2 March 2011 10:19

To: info@mindgarden.com

Dear Valorie

Thank you very much for the inventories. I see that there are quite a few translations and none are an "official version". I gather then that it is alright to use bits and pieces from the different versions and use my own wording if I think more appropriate? As I said in my previous mails, some of the questions will in integrated in a new questionnaire, which will be validated for the population I am going to work with (health care workers who care for the dying).

best wishes

Carol

---

info@mindgarden.com <info@mindgarden.com> 3 March 2011 19:24

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

yes, that is fine.
Best,
Val

APPENDIX 10 - AUTHORIZATION FROM PSYCHTESTS AIM INC TO USE THE BURN-OUT TEST

From: Testyourself Contact Us [mailto:carolgouveiamelo@gmail.com]
Sent: Wednesday, May 11, 2011 1:56 PM
To: contact@psychtests.com
Subject: General inquiry about PsychTests

From: carol gouveia melo.
Email: carolgouveiamelo@gmail.com.

Message: In 2001 I used a few of your questions from a test you had on burnout to
construct a questionnaire on burnout for health care workers who care for dying patients in
Portuguese
hospitals. At the time, your tests were free to download. I am now writing a scientific
report
for a journal. May I say in my report that I have your authorization? The questions used
were the
following:
- I would be incapable of coping with my work if I considered my patients as unique individuals
- I don't really care what happens to my patients
- I cannot afford to answer to the individual needs of my patients.
- I feel that what I do makes a difference
- I feel that other people have realistic expectations regarding my working performance

Thank you for your collaboration
Carol Gouveia e Melo.

Jeannette <contact@psychtests.com> 12 May 2011 22:17

To: carolgouveiamelo@gmail.com

Hello Carol,

You can use the 5 questions you enumerated below in you work. However, you will be required to indicate this reference in all pages containing the licensed materials, to wit:

Reference: Jerabek, I. Ph.D. (2001). Burnt-out Test. PsychTests Aim Inc.

We would also appreciate if you could send us a copy of the materials in which our questions are used.

Good luck!
Best regards,
Jeannette

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 13 May 2011 09:21

To: Jeannette <contact@psychtests.com>

Dear Jeanette

Thank you very much.

Am attaching the questionnaire (I forgot to say that the questions were translated into Portuguese, because the study was performed in Portugal.

When the article is published, will send it to you as well.

Best wishes

Carol Gouveia e Melo

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 13 May 2011 09:27

To: Jeannette <contact@psychtests.com>

Dear Jeanette

I suppose I should also have an e-mail from you saying that I can translate the questions. I am sorry - I should have said this in my original e-mail.

best wishes

Carol

Jeannette <contact@queendom.com> 13 May 2011 19:27

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 25 October 2011 00:08

To: Jeannette <contact@psychtests.com>

Dear Jeannette

I wrote to you a while ago asking permission to use some questions from your burnout questionnaire. You said that the reference was: Jerabek I. Burnout test. Montreal: PsychTests AIM; 2001.

The Journal of Palliative Care, who are going to publish the article are now asking me more information for the reference section :

[In what form was this test published? Is it a Web document? If so, please provide exact title and url.]

Could you let me know the full details?

Thank you

Carol

PS: they want my answer by Wednesday. sorry to pressure you

On 12 May 2011 22:17, Jeannette <contact@psychtests.com> wrote:

Jerabek, I. Ph.D. (2001). Burnt-out Test. PsychTests Aim Inc.

Jeannette <contact@psychtests.com> 25 October 2011 15:02

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

Hello Carol,

As per your request, here are the additional details of the test:

a. It is an online test

b. We have two versions of Burn-out Test that are available now in the market. You can choose any of these versions:

- Burnout Test (Service Fields) = http://testyourself.psychtests.com/testid/2079

- Burnout Test (Non-Service Fields) = http://testyourself.psychtests.com/testid/2080

We could no longer provide you the link to the old version of the Burn out Test where your test questions were taken because it is no longer active.

Hope this meets your requirement.

Best regards,
Jeannette

Carol Gouveia Melo <carolgouveiamelo@gmail.com> 25 October 2011 18:17

To: Jeannette <contact@psychtests.com>

Dear Jeanette

Thank you. I think that should be enough. I presume I used the service field burnout test, although I couldn't check, because although I signed in, I couldn't manage to fill in the test (nothing happens when I click on the dots) and I can't enter page two of the questionnaire without filling in page 1!

Carol

Jeannette <contact@queendom.com> 25 October 2011 18:27

To: Carol Gouveia Melo <carolgouveiamelo@gmail.com>

Hello Carol,

I checked on the test and everything is working fine. You need to fill-up or answer all questions in each page before you can move to the next page.

By the way kindly revise the reference information that I gave you to this:

Jerabek, I. Ph.D. (2001). Burnt-out Test (Service Fields). PsychTests Aim Inc.

http://testyourself.psychtests.com/testid/2079

Please indicate the above reference in all pages containing the licensed materials.

Hope this helps!

Best regards,

Jeannette

APPENDIX 11 - SURVEY TO ASSESS HEALTH CARE PROFESSIONALS' DIFFICULTIES WORKING WITH PATIENTS WITH A TERMINAL CONDITION

Professional Problems in casring for patients with a terminal condition that contribute towards burnout

Fear of not having sufficient or adequate knowledge (2)

Repeated "non-response" to therapeutics, in spite of strong (4) (not adering to medication)

Feelings of helplessness to alleviate fragility

Problems of family dynamics that interfere with the patient and are dificult to treat

Unexpected death in spite of the terminal illness

Relieving the patient's pain

Get the family to understand the disease and help in the treatment

Fear of not being able to help the patient

Fear of not being up to it

Lack of compreension of the team towards their colleagues who are more caring (more focused on the patient and family) and less technical

Lack of coordination and bad relationships within the team (2)

Institutional demands for productivity and false humanity at the various levels of administration/superiors

Tireness caused by work overload

Inadequate pay in relation to professional responsibilities and personal needs which almost always leads to the use and abuse of accumulated jobs

Lack of comprehension of behalf of the family and friends about the needs/ wishes of the patient

In capacity on behalf of the population to see the health care worker as a human being with feelings, personal life, personal problems, a person that eats, ressts, goes to the loo. The nurse is often seen as a worker who is paid and therefore is obliged to be there at their disposition 24 hours a day.

Incapacity to cope with people's conscious incompetence.

Lack of specific deeper training in palliative care

Not knowing what to say to the family and patient when they ask so many questions. (2)

Lack of nurses that does not allow us to give more time to talk to patients. (3)

Lack of debate within the team of difficulties experienced.

Lack of physical conditions that prevent privacy and the family to stay close (3)

Managing conflict within the team

Children or young patients (5). It makes us angry and then it is difficult to establish a helping relationship.

Young patients because we know what it is like to be in their place

Mothers with young children (2)

Repeated deaths and coping with the families' sadness

Demanding families

Feelings of helplessness when death arrives

Feelings of frustration and helplessness when I can't completely satisfy the patients' and families' needs

When the patient or family feel very angry with the situation and can't accept death, I feel that care is more demanding and there is more emotional exhaustion.

Lack of a full team: psychologist, nurse, doctor, social worker, priest etc.

The health system is not set up to care for the "dying"

Lack of time to establish a helping relationship with patients and families.

Sometimes I get very involved with patients in the terminal phase, and this really leads me to intense physical exhaustion and sometimes leads me to think about the meaning of life, and if it is all worthwhile.

After establishing a deeper relationship, having the feeling that more could have been done and that I did not deal with the patient's and family's needs in the best way. (2)

What fulfills you

When I really have time to "be" with the patient/family

To listen to the patient/family with time and no hurries (2)

When the patient/family treats me like "family" and not as the nurse who is untouchable, emotionless and just a worker.

When the patients/families' pain is reduced

When I share a hug, a smile, a caress, a tear.

When I can one day be part of a team that gives more importance to the patient as a person than as a statistic.

When the “hour of death” is identified, respected and lived in harmoney by the nurse, family and team.

When the patient and family feel supported in their home as a family, with quality of life and dignity.

The patients help me to live one day at a time

The patients help me to give more value to what I do and to what I have.

To establish a relationship with the family and patient

Giving them hope and meaning in life (2)

Being able to help when there is “nothing else to do”

Giving support when I have knowledge in this area of care

To be able to provide and end of life with quality, comfort and dignity

When the patient is able to give value to small things and find some meaning in this last phase of life.

When I am able to overcome my barriers and am able to help the patient find meaning in life, when I am able to help in the teminal phase, when I am able to laugh and cry with the him, when I am able not to say things like “be calm”, or “be patient” and when I am able to not take away their hope.

When I feel that it is worth while being a nurse because I was able to help the patient live the time he had left in the best possible way.

After getting to know the patients, I give more value to what really matters in life

Being with the patient helps me grow as a person

Fears in relation to life that may affect you and how this may affect your professional life

Fear of physical suffering (9)

Causing suffering in others

Fear of emotional fear

Fearsof death. I avoid thinking about it

Loneliness

Fear of separation and of suffering in people I care for (4)

Losing a friend

Losing family members

Fear of loosing my stability and happiness when someone I live dies or gets sick

Losing my mother

Having a physical incapacity that conditions a lot my physical activity (2)

Transforming myself into someone frustrated and bitter with life

Fear of failing

Fear of mental disturbances in family members

Fear of going out at night to do emergencies

Fear of not being able to help enough

Fear of not understanding the patients' needs

Fear of not being near when the end is near

Fear of not realising when it is the end

Fear of comitting the mistake of doing everything for the patient because he is incapacitated and diminishing him even more.

Depending on others

Dying young and leaving a lot to be done (2)

Fear of not aprreciating and doing what is really worthwhile in life.

Feeling tired due to my family life influences the way I look at the patient and my internal availability for him.

Fear of the unknown: how will things be? – specially in relation to death

Fear of not being able to see beyond the patient's appearance and not being able to reach him

Fear of becoming attached to the patient and then suffering

Fear of saying goodbye

Fear of sharing about my fear of death and suffering that is associated to dying and that the people I want to talk to will avoid the converstaion and not be available to talk about these matters.

Fear of wht comes after death

Difficulties in the helping relationship

Fear of invading the patient's space

Knowing how far I can go during the first consultation

Understanding non verbal communication, namely that of the family/carer

Difficulty in dealing with the patients hope in face of the inevitable

Hiding whast I am feeling on a “bad day” and that this may transpsire in the relationship. Pastients try tio help and I don’t allow it, so I push them away.

Establishing a relationship with a patient that arrives in the unit in a terminal state without having had time to be prepared by the team.

I have no difficulties.I have 7 years of experience and am able to establish a relationship quickly.

Being assertive (I don’t know what to say or how to say it)

Sometimes I am unable to attend to patients’ needs in the best way, for example, what can I do to help the patient accept his situation and have a pacific end of life.

My own fear of death sometimes limits me in understanding the needs of patients.

Difficulty in controling my emotions and so I avoid the patient.

Difficulty in understanding when the terminally ill patient wants to talk about the matter, when he just wants a presence or when he wants to be alone.

Difficulty in understanding the non verbal language, or the meaning of what is behind the patient’s words.

Difficulty in approaching the subject with the patient or his family

Difficulty in understanding what the patient is feeling without getting emotional.

The fears that I feel sometimes don’t allow me to listen to what the patient is really saying and make me say things that I want to hear and would like to be true.

Difficulty in understanding the patient’s world because he is confused (2) or alienated.

Difficulty in recognising a cry for help from the patient or family

When the patient can’t talk, I don’t know whether I am in tune with his emotional needs

When I am unable to unconditionally accept the patient because I judge him according to my values. I think I am doing him harm.

Fear of the future, because sometimes there are a lot of uncertainties, but I try to put myself in the place of the patient and help him open up and I try to share the fears so we can face them together, and that makes me suffer.

It helps me to try to understand what the patient knows about his illness and what is his understanding of his surroundings (family and community)

Because I fear death and don’t think about her, I find it difficult to be near dying patients because I don’t think I will be able to the necesary peace.

Fear of not being able to answer the patient’s questions

Having been through difficult experiences helps me not to run away from these situations.

Sometimes I feel like avoiding a relationship with the patient and family.

Fear of not having made the other person feel worthy.

Not having told the patients what I learnt with them.

How to approach the theme of death

How to know what is important for the person

The temptation of avoiding conversations with the patient

The main obstacle in the helping relationship is distance, not being able to give support, avoiding being close, feeling nervous and anxious which leads to lack of presence, incapacity to “be” and feel which lies underneath this inner “noise”

Difficulty in allowing closeness with the patient because it reminds us of personal situations (3)

My fears lead me to have an attitude of overrprotection (2)

Tendency to talk more from a rational point of view than emotional

Not having “solutions” to the problems people dhave and questions they ask

End of life psychological/cognitive degradation

APPENDIX 12 - QUESTIONNAIRE TO ASSESS HELPING RELATIONSHIP (BEFORE AND AFTER TRAINING)

Barrett-Lennard Relationship Inventory Id nº________

Following is a list of several statements related to burnout in health care workers. They are to evaluate your risk of burnout in relaton to your work.

Consider ech statement with respect to yourself in general.

Opn the right hand side of the page, put a cross for each statement from 1 to 6 where:

1 = I disagree completely and 6 = I agree completely

This questionnaire is anonymous. It is important for this project that you answer all questions sincerely, and avoiding “socially desirable” answers.

Thank you for the time you have given to me

I DISAGREE COMPLETELY

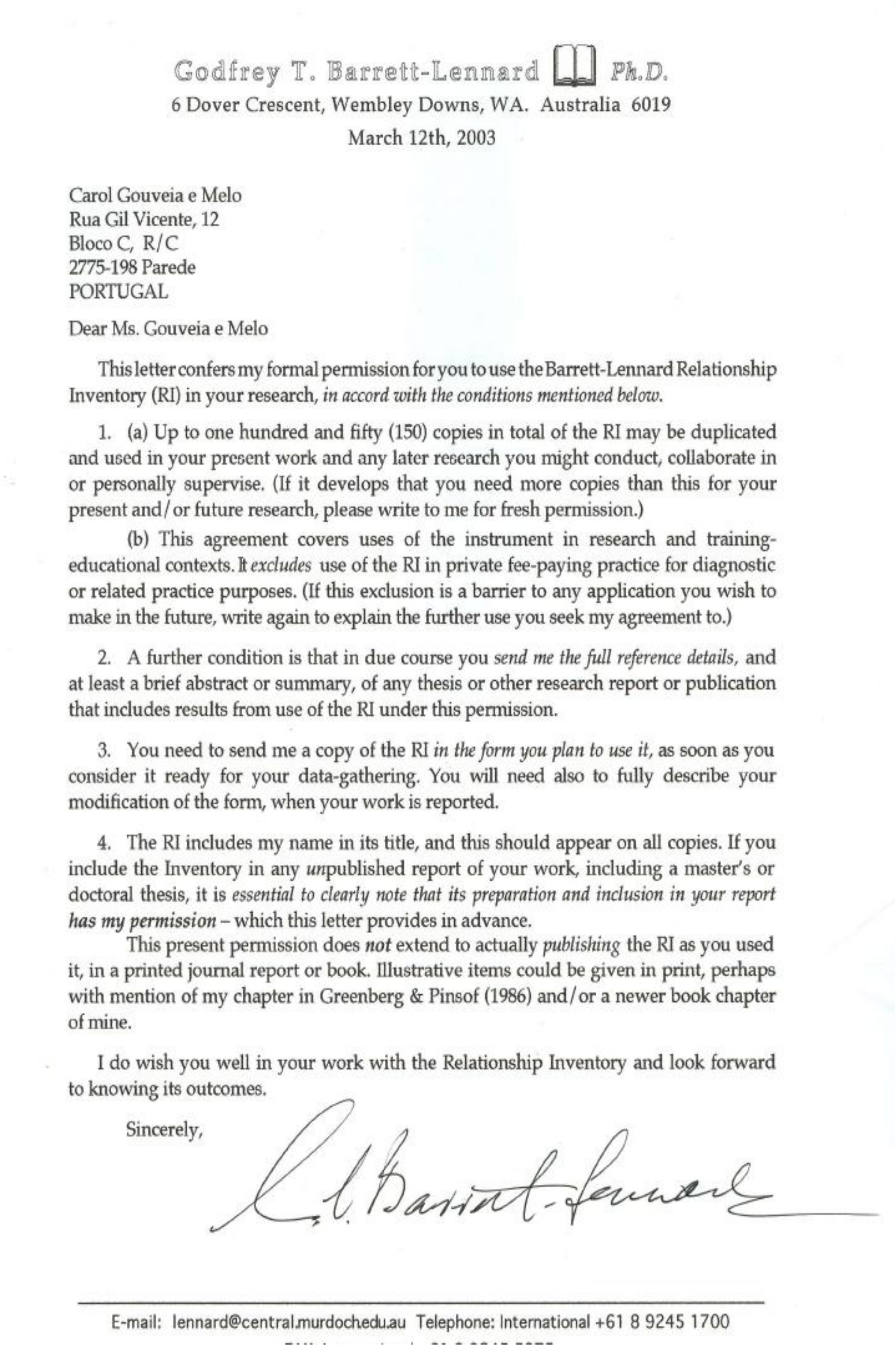
I AGREE COMPLETELY

1	I respect them as people.	1	2	3	4	5	6
2	I usually sense or realize how they are feeling.	1	2	3	4	5	6
3	The interest I feel in them depends on their words and actions.	1	2	3	4	5	6
4	I tend to put on a role or front with them.	1	2	3	4	5	6
5	I like them.	1	2	3	4	5	6
6	I hear their words, but don’t know how they feel inside.	1	2	3	4	5	6
7	Whether they are feeling happy or unhappy with themselves doesn’t make me feel more or less positive towards them.	1	2	3	4	5	6
8	I don’t avoid or put off dealing with anything that matters between us.	1	2	3	4	5	6
9	I feel indifferent to them.	1	2	3	4	5	6
10	I nearly always see exactly what they mean.	1	2	3	4	5	6
11	Depending on their actions, I have a better opinion of them sometimes than I do at other times.	1	2	3	4	5	6
12	I feel that I am genuinely myself with them.	1	2	3	4	5	6
13	I appreciate and value them as people.	1	2	3	4	5	6
14	At the time, I don’t realize how touchy or sensitive they	1	2	3	4	5	6

	are about some of the things we discuss.						
15	My liking or disliking of them isn't changed by anything they say about themselves.	1	2	3	4	5	6
16	I don't show my inner impressions and feelings with them.	1	2	3	4	5	6
17	I find them rather dull and uninteresting.	1	2	3	4	5	6
18	I can tell what they mean, even when they have difficulty saying it.	1	2	3	4	5	6
19	I would like them to be a particular kind of person.	1	2	3	4	5	6
20	I am willing to say whatever is in my mind with them, including feelings that come up in me about either one of us, or how I see us getting along.	1	2	3	4	5	6
21	I care for them.	1	2	3	4	5	6
22	I screen out and don't pick up on some of their feelings.	1	2	3	4	5	6
23	If they get impatient or mad at me, I become angry or upset too.	1	2	3	4	5	6
24	I am able to be openly myself in our relationship.	1	2	3	4	5	6
25	I do feel disapproval of them.	1	2	3	4	5	6
26	I usually can tune in and understand all of their meaning.	1	2	3	4	5	6
27	Whether they are expressing 'good' thoughts and feelings, or 'bad' ones, does not affect the way I feel towards them.	1	2	3	4	5	6
28	Sometimes I am not at all comfortable with them, but we go on, outwardly ignoring it.	1	2	3	4	5	6
29	I feel friendly and warm towards them.	1	2	3	4	5	6
30	I really don't understand them.	1	2	3	4	5	6
31	The way I feel about them doesn't depend on their feelings towards me.	1	2	3	4	5	6
32	I know exactly what I feel in relation to them. I don't sense anything that's hard to face and admit to myself.	1	2	3	4	5	6
33	I put up with them.	1	2	3	4	5	6
34	I appreciate just how their experiences feel to them.	1	2	3	4	5	6
35	Sometimes they seem to me a more worthwhile person than they do at other times.	1	2	3	4	5	6

36	There are times when my outward response to them is quite different from the way I feel underneath.	1	2	3	4	5	6
37	I do feel impatient with them.	1	2	3	4	5	6
38	I respond to them rather automatically, not always taking in what they are experiencing.	1	2	3	4	5	6
39	I don’t think that particular things they say or do alter the way I feel towards them.	1	2	3	4	5	6
40	It bothers me when they try to ask or talk about certain things.	1	2	3	4	5	6

APPENDIX 13 - AUTHORIZATION TO USE THE BARRETT-LENNARD RELATIONSHIP INVENTORY



Godfrey T. Barrett-Lennard Ph.D.
6 Dover Crescent, Wembley Downs, WA. Australia 6019

March 12th, 2003

Carol Gouveia e Melo
Rua Gil Vicente, 12
Bloco C, R/C
2775-198 Parede
PORTUGAL

Dear Ms. Gouveia e Melo

This letter confers my formal permission for you to use the Barrett-Lennard Relationship Inventory (RI) in your research, *in accord with the conditions mentioned below.*

1. (a) Up to one hundred and fifty (150) copies in total of the RI may be duplicated and used in your present work and any later research you might conduct, collaborate in or personally supervise. (If it develops that you need more copies than this for your present and/or future research, please write to me for fresh permission.)

(b) This agreement covers uses of the instrument in research and training-educational contexts. It *excludes* use of the RI in private fee-paying practice for diagnostic or related practice purposes. (If this exclusion is a barrier to any application you wish to make in the future, write again to explain the further use you seek my agreement to.)

2. A further condition is that in due course you *send me the full reference details,* and at least a brief abstract or summary, of any thesis or other research report or publication that includes results from use of the RI under this permission.

3. You need to send me a copy of the RI *in the form you plan to use it,* as soon as you consider it ready for your data-gathering. You will need also to fully describe your modification of the form, when your work is reported.

4. The RI includes my name in its title, and this should appear on all copies. If you include the Inventory in any *un*published report of your work, including a master's or doctoral thesis, it is *essential to clearly note that its preparation and inclusion in your report* ***has my permission*** – which this letter provides in advance.

This present permission does ***not*** extend to actually *publishing* the RI as you used it, in a printed journal report or book. Illustrative items could be given in print, perhaps with mention of my chapter in Greenberg & Pinsof (1986) and/or a newer book chapter of mine.

I do wish you well in your work with the Relationship Inventory and look forward to knowing its outcomes.

Sincerely,

G.T. Barrett-Lennard

E-mail: lennard@central.murdoch.edu.au Telephone: International +61 8 9245 1700

APPENDIX 14 - QUESTIONNAIRE TO ASSESS PERSONAL WELL-BEING (BEFORE AND AFTER TRAINING)

QUESTIONNAIRE ON PERSONAL WELL-BEING ID Nº____

Following is a list of several statements related to burnout in health care workers. They are to evaluate your risk of burnout in relaton to your work.

Consider each statement with respect to yourself in general.

Opn the right hand side of the page, put a cross for each statement from 1 to 6 where:

1 = I disagree completely and 6 = I agree completely

This questionnaire is anonymous. It is important for this project that you answer all questions sincerely, and avoiding "socially desirable" answers.

Thank you for the time you have given to me

I DISAGREE I AGREE

COMPLETELY COMPLETELY

1	I have many real friends whom I can count on.	1	2	3	4	5	6
2	I face challenges with quite a lot of internal confidence.	1	2	3	4	5	6
3	Apart from my physical aspect, I also value the emotional and spiritual side of me.	1	2	3	4	5	6
4	If I have to die, may it be quick.	1	2	3	4	5	6
5	I feel fulfilled in my profession.	1	2	3	4	5	6
6	If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them.	1	2	3	4	5	6
7	I normally feel quite unconfident when faced with the unknown.	1	2	3	4	5	6
8	I cannot feel that I am of value if I do not have a good physical appearance.	1	2	3	4	5	6
9	Deep down, I know that I can tolerate more physical pain than I think.	1	2	3	4	5	6
10	I spend a lot of time doing activities I do not like.	1	2	3	4	5	6
11	I often think about my relationships to see if there is any unfinished business with anyone.	1	2	3	4	5	6
12	I feel I have strategies and inner strength to deal with unforeseen situations that appear in my life.	1	2	3	4	5	6
13	My dignity does not depend just on my usefulness in	1	2	3	4	5	6

	society.						
14	Without physical health, it is not worth living.	1	2	3	4	5	6
15	Right now, I think that my life has meaning.	1	2	3	4	5	6
16	With regard to my relationships, I normally put a stone on matters that disturb me.	1	2	3	4	5	6
17	I am not at ease until I have everything “under control”.	1	2	3	4	5	6
18	If I cannot be an active and independent person, my life would lose all meaning.	1	2	3	4	5	6
19	I know that physical weaknesses will not stop me from continuing to contribute towards giving meaning to my life.	1	2	3	4	5	6
20	There is no balance in my life between obligations and leisure.	1	2	3	4	5	6
21	I make a point of finding time in my life to be with friends.	1	2	3	4	5	6
22	I normally accept what I cannot change.	1	2	3	4	5	6
23	I can accept aging and the gradual degradation of my body as a natural stage in life.	1	2	3	4	5	6
24	The time of dying has no value. It is best to die quickly to end the suffering.	1	2	3	4	5	6
25	I find ways to feel fulfilled in every-day life.	1	2	3	4	5	6
26	I often do not show my appreciation to friends and family, and then regret it.	1	2	3	4	5	6
27	I feel the need to be informed of everything that surrounds me.	1	2	3	4	5	6
28	If I become ill, I would rather die than become dependent on others.	1	2	3	4	5	6
29	I accept that physical pain, like any other, is part of life, whether it is my pain or other people’s pain.	1	2	3	4	5	6
30	I still need to identify what I still want to do in life before dying.	1	2	3	4	5	6
31	I normally phone friends and family, just to see how they are.	1	2	3	4	5	6
32	I accept difficult situations as part of my life journey and personal growth.	1	2	3	4	5	6

33	I feel the same person, even when I am not happy with my physical appearance.	1	2	3	4	5	6
34	I would rather die than be in physical pain.	1	2	3	4	5	6
35	If I only had a short while to live, I think I would continue to do more or less what I am doing today.	1	2	3	4	5	6
36	I normally feel resentment towards others without trying to find a solution.	1	2	3	4	5	6
37	I do not feel capable of dealing with big changes in the “status quo” of my life.	1	2	3	4	5	6
38	I am afraid of being a burden to others.	1	2	3	4	5	6
39	In spite of the physical pain that I may suffer from, life will continue to have meaning.	1	2	3	4	5	6
40	I spend a lot of time trying to give well-being to others, with damage to my own well-being.	1	2	3	4	5	6
41	I normally tell people I love, what they mean to me.	1	2	3	4	5	6
42	I feel that I have external resources to overcome the more complicated moments of my life.	1	2	3	4	5	6
43	My body is not perfect, but I like it all the same.	1	2	3	4	5	6
44	I cannot conceive living with a big physical disability.	1	2	3	4	5	6
45	If I only had one more year to live, there would not be many things I would stop doing because they are a waste of time.	1	2	3	4	5	6
46	I am always in a hurry and do not always notice or thank the caring gestures of other people.	1	2	3	4	5	6
47	I do everything I can to avoid any difficulties or instabilities in my life.	1	2	3	4	5	6
48	Physical degradation frightens me. It makes me feel reduced to nothing.	1	2	3	4	5	6
49	I trust that when the time comes, I will receive what I need to deal with my physical pain.	1	2	3	4	5	6
50	I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life.	1	2	3	4	5	6

APPENDIX 15 - VALIDATION OF QUESTIONNAIRES

1 Validation and reliability of the questionnaires

Apart from the questionnaire on existential well-being, which was developed and validated specifically for this research, the previous sections describe the questionnaires as they were originally designed and validated by their authors. However, it was considered important to submit all three questionnaires to new validation tests to obtain certainty that they were in fact measuring what they were originally designed to. Although a questionnaire may be designed logically, following theoretical studies, and submitted to validation tests, it is not possible to foresee all the characteristics of a different sample to be certain that they will all perceive and interpret the questions in the same way. For example, the MBI was originally validated in America, and the Barrett-Lennard Inventory in Australia, but the sample of this research was composed of Portuguese nurses who come from a different culture and their nursing training may also be different, for example focusing more on the technical and medical aspects of nursing compared to the human side or vice versa. Also, within the nursing profession, these nurses come from a specialized area – death and dying - which may cause them to differ even more from other populations. The following paragraph will explain how this can affect the interpretation of the questionnaires.

Questionnaires are designed with groups of questions that measure one dimension. For example, the Barrett-Lennard Inventory measured four different aspects of helping relationship attitudes: positive regard, empathy, unconditional acceptance and congruence. By performing principal component analyses (PCAn), it is possible to certify that these participants are perceiving these four dimensions as separate groups, and if not, they will be regrouped according to the results of the PCAn, and renamed by the researcher, who will look at how the items have been grouped, to make sense of them. Possible outcomes are that two dimensions are collapsed into one, or on the contrary, the dimensions may become smaller and more numerous. It is also possible that PCAn can result in separating positive and negative questions in separate dimensions. Only once this has been done, can the items be correctly summed as dimensions, to prepare for statistical analysis. These validation tests are an important part of the research, as all the quantitative results are based upon the results of these analyses. The following paragraphs will describe the methodology of these validation analyses.

The initial questionnaires were submitted to a pilot test with 10 participants who were debriefed to ensure that all questions were understood as intended. Ethical consent of the clinical director of each hospital department was obtained to distribute the questionnaires to the HCWs who agreed to participate in a research project to understand if an intervention comprising of education together with personal introspection relating to death anxiety could reduce burnout and improve the quality of care and relationship with patients and their families.

The questionnaires were filled in by HCWs who had not yet received the intervention. They were each given a cover letter explaining the research project and an identification sheet with demographic data (age, sex, place of work - in or out of a palliative care unit, - level of education, profession and marital status.). Anonymity was assured. The questionnaires were collected for sensitivity tests, construct, convergent and divergent validation and tests of internal consistency.

Four months later, the questionnaires were distributed again to the participants who had completed the intervention and test-retest reliability analyses were performed.

The validation of the questionnaires used in this study was performed using the questionnaires from both the intervention and the control group.

The literature shows conflicting opinions on how many participants are needed to validate a questionnaire. Nunnally (1978) has suggested 10 participants for each variable. Kass and Tinsley (1979) recommend between 5 and 10 participants up to a total of 300 participants, at which point they consider test parameters to be stable regardless of the ratio between the number of participants and the number of variables. The view that 300 participants is sufficient has been supported by other researchers (Tabachnick & Fidell, 1996) and (Comrey & Lee, 1992) and the latter also add that 300 is a good sample size, 100 is poor and 1000 is excellent. Finally, a study by Arrindell and van der Ende (1985) concluded that changes in the ratio made little difference to the stability of factor analysis. This shows that there is not a clear consensus on the actual number needed for adequate validation.

However, the ratio of participants to variables has not been the only criteria to effectively perform factor analysis. A study by Guadagnoli and Velicer (1988) considered the absolute magnitude of factor loadings to be more important. They suggest that 4 or more loadings greater than 0.6 is reliable regardless of the size of the sample or 10 or more loadings greater than 0.4 is reliable if the sample is greater than 150. However, the drawback of this system, is that one needs to perform the validation studies in order to decide whether the sample is adequate.

Based on this information, and considering that the largest questionnaire in this study has 50 items, the aim was to obtain 300 participants, and if this was not possible, a minimum of 250 participants, to fulfill the criteria of a minimum of 5 participants per item. The aim was also to obtain an equal amount of HCWs who worked in palliative care units and those who cared for patients with a terminal condition out of palliative care units and to include all professional categories that participated in the care of the patient, such as doctors, nurses, nursing aides, psychologists, chaplains, physiotherapists and occupational therapists, in proportionate numbers in relation to the constitution of the team. After the completion of the validation tests, the factor loadings would be analyzed for confirmation.

Of the 300 scales that were delivered to HCWs who cared for patients with a terminal condition, 280 were returned (response rate, 93.33%). Of the 280 initial responses, 150 HCWs agreed to take the retest, all of which were returned. Of the 280 questionnaires, 208 were delivered personally and checked immediately for missing data and these were filled in by the participant at the time. The remaining 72 were checked for missing data at a later date; ten were found having missing values and were filled in using the mean score of the item.

The 280 participants used for sensitivity tests and construct validation were health care workers in Portugal, aged 21 to 67, comprising of 177 (63,2%) nurses, 62 (22,1%) nursing aides, 13 (4.6%) psychologists, 11(3.9%) doctors, 8(2.9%) social workers, 3 (1.1%) physiotherapists, 2 (0,7) secretary, 1 (0,4) occupational therapist, 2(0,7) chaplain, 1 (0,4%) nutritionist. 247 (88.2%) were female and 33 (11.8%) male. 124 (44.3%) worked in palliative care units and 156(55.7%) worked with patients with a terminal condition but not within a palliative care unit. Most of the participants worked in oncology hospitals, both in the centre and north of Portugal and others worked in community home care. The characteristics of the 150 participants used for convergent, divergent and reliability tests are described in the previous section.

Tests for sensitivity of the individual items, construct, convergent and divergent validation and tests-retest analyses were performed for each questionnaire. Following is a summary of the most important results.

1.1 Validation and reliability of the burnout questionnaire

1.1.1 Sensitivity

Sensitivity tests were performed to find items that were abnormally distributed, i.e. excessively skewed or kurtosed. This showed that most items fell within the acceptable range of -3.0 to + 3.0 for skewness, and -8.0 to + 8.0 for kurtosis. Items 18 and 24 showed inadequate sensitivity values and this should be taken into consideration in the future use of the questionnaire. For a Likert scale of 1 to 6, an acceptable median would be within the range of 3 to 4. This is the case for items relating to emotional exhaustion. However, results were skewed for items relating to professional fulfillment and depersonalization. This is to be expected with this sample. Whereas it is feasible for HCWs to suffer from emotional exhaustion, for example due to excessive contact with death and suffering, and work overload, it is not expected that they would show attitudes of depersonalization with patients who are fragile, vulnerable and dying. Likewise, due to the close and caring relationship with patients, this work is professionally rewarding and brings meaning into the lives of these HCWs. For this reason, these items were maintained for factor analysis.

1.1.2 Construct validation

The 40 items of the scale were subjected to principal components analysis (PCAn) and three factors were extracted. After examination of the individual items of each factor, it was decided to name each factor as follows:

Emotional exhaustion (a depletion or draining of emotional resources) (Maslach, et al., 1997)

Depersonalisation (a development of negative, callous and cynical attitudes towards the recipients of one’s services). (Maslach, et al., 1997)

Professional fulfilment (a sense of well-being at work)

Alpha Cronbach test (α C) was performed on the final factors.

The following table shows a summary of the results:

BURNOUT (n= 280)	T1
Emotional exhaustion (α C 0,86)	F1 V14,67%

ee 1	I feel emotionally drained by my work	.766
ee 15	I feel worn out	.764
ee 6	I feel tired when I get up in the morning and have to face another day of work	.717
ee 20	I have no strength left at the end of a day's work	.608
ee 23	I feel that I work too hard in my profession	.568
ee 13	I am frustrated because I cannot find the time to have a quality relationship with the patient	.555
ee 21	Dealing psychologically with terminally ill patients makes me feel insecure and anxious	.545
ee 35	I feel stressed due to the lack of debate and support within the team, with regard to our difficulties	.502
ee 10	I feel helpless when faced with the patient's fragility	.495
ee 28	The relationship with the patient's family wears me out	.491
ee 38	I ask myself many times if I could have "done more" and this makes me feel anxious	.491
ee 8	I feel frustrated by my work	.477
ee 25	I am emotionally disturbed by the death of so many patients	.469
ee 31	Working directly with people causes me a lot of stress	.445
d 27	I cannot afford to answer to the individual needs of my patients	.303
Professional fulfillment (α C 0,83)		F2 V 10,87
pf 32	I have a positive influence on the people I coordinate at work.	.728
pf 14	It is easy for me to create a relaxed atmosphere with other people	.628
pf 3	I resolve other people's problems efficiently	.603
pf 40	I often contribute towards giving my patients quality of life, comfort and dignity at the end of their life	.586

pf 22	I feel that what I do makes a difference	.582
pf 26	At work, I deal with emotional problems very calmly	.575
pf 29	I feel that other people have realistic expectations regarding my working performance	.532
pf 19	I have accomplished many useful things in this work	.488
pf 5	I can easily understand what other people are experiencing	.486
pf 33	I have moments of sharing with the patients, with no need to hid my feelings	.442
pf 17	I feel fulfilled when I work in close collaboration with others	.434
pf36	I feel energetic	.413
pf 39	I manage to find time in my work to talk to patients and to help them find meaning in their lives	.396
pf 9	I feel fulfilled at work because I manage to find time to just "be" with the patient and their family	.338
Depersonalization (α C 0,69)		F3 V8,2%
d 24	I don't really care what happens to my patients	.578
d 7	I have become more insensitive to people since I have this job	.563
d 30	I give more importance to the technical part of my work than to the human part	.537
d 12	I am afraid this job will make me become emotionally hard	.492
d 16	I do not pay real attention to what happens to other people	.470
d 34	I give a lot of importance to treating the illness, but do not have patience for the psychological and spiritual caring of the patient	.466
d 2	I feel that I treat many people impersonally, as if they were objects	.451
ee 18	Working everyday with people is a real burden for me	.359
d 4	I would be incapable of coping with my work if I considered my patients as unique individuals	.353

Note: ee = emotional exhaustion; d = depersonalization; pf = professional fulfillment;

α C = Cronbach's Alpha; M = mean; SD = standard deviation; V = variance.

TABLE 1 - FACTOR ANALYSIS OF BURNOUT QUESTIONNAIRE

1.1.3 Convergent and divergent validation

The relationships between burnout, death anxiety and quality of helping relationships were investigated using Pearson product-moment correlation coefficient. Many strong and medium strength correlations were found.

1.1.4 Reliability

Cronbach alpha coefficients were .86 for factor 1, .83 for factor 2 and .69 for factor 3. The acceptable value for Cronbach alpha is .7. In order to establish test-retest reliability, Pearson bivariate correlations were performed on the 3 factors, with an interval of 4 months and results showed that all three factors are reliable both internally and over time.

1.2 Validation and reliability of Barrett-Lennard Questionnaire

1.2.1 Sensitivity

Sensitivity tests were performed to find items that were abnormally distributed, i.e. excessively skewed or kurtosed. Results showed that most items fell within the acceptable range of -3.0 to + 3.0 for skewness, and -8.0 to + 8.0 for kurtosis. Items 1, 17 and 9 showed inadequate sensitivity values and this should be taken into consideration in future use of this questionnaire. For a Likert scale of 1 to 6, an acceptable median would be within the range of 3 to 4. This was only the case for items relating to avoidance mechanisms and empathy and congruence. Results were skewed for items relating to unconditional acceptance and distance and impatience. This is to be expected with this sample. It is not expected that they would show attitudes of distance and impatience with patients who are fragile, vulnerable and dying. Likewise, they are not expected to have a judgemental attitude towards these patients, but rather show them unconditional acceptance. For this reason, these items were maintained for factor analysis.

1.2.2 Construct validation

The 40 items of the scale were subjected to principal components analysis (PCAn) and four factors were extracted. After examination of the individual items of each factor, it was decided to name each factor as follows:

Empathy and congruence: "Empathy and congruence": a continuing process whereby the HCWs lay aside their own way of experiencing and perceiving reality, preferring to sense and respond to the experiences and perceptions of the patient. This sensing may be intense and enduring with the HCWs actually experiencing the patient's thoughts and feelings as powerfully as if they had originated in themselves, but the HCWs are comfortable and able to cope with this. (Mearns, D., Thorne, B., 1988)

Unconditional acceptance: the label given to the fundamental attitude of the person-centred counsellor towards her client. The counsellor who holds this attitude deeply values the humanity of her client and is not deflected in that valuing by any particular client behaviours. The attitude manifests itself in the counsellor's consistent acceptance of and enduring warmth towards her client (Mearns, D., Thorne, B., 1988)

Distance and impatience: in this context, this factor refers to the opposite attitude portrayed by unconditional acceptance).

Avoidance mechanisms: (feelings of uneasiness with issues related to suffering and death which can lead the HCWs to subconsciously protect themselves by avoiding certain conversations and avoiding a close, genuine relationship with the patient). It should be noted that these questions were not designed specifically to measure avoidance mechanisms in HCWs who care for patients with a terminal condition, but were part of a questionnaire to measure the attitudes in a helping relationship. They measured empathy, congruence and unconditional acceptance. This is why some of the questions may seem out of context as specific avoidance mechanisms. However, validation of the questionnaire in this population grouped the questions in a different order and when considering the set as a whole, they seemed to be showing attitudes of avoidance. Question nº ua35 of table 3 was created to measure unconditional acceptance and nº e14 was created to measure empathy. However they make sense within this group of questions, because when the HCW is uncomfortable with the situation, they may become more centred on their own feelings of uneasiness than on the patient and consequently lose some of their capacity to empathize, or they can become more judgemental: it is easier to feel justified in avoiding a patient if one can find faults in them (Rogers, 1951).

Alpha Cronbach (α C) test was performed on the final factors. The following table shows a summary of the results

HELPING RELATIONSHIP – POSITIVE ITEMS (n =280)		T1
Empathy and congruence (α C 0,82)		F1 V 20,73%
e26	I usually can tune in and understand all of their meaning	.723
e10	I nearly always see exactly what they mean	.689
e18	I can tell what they mean, even when they have difficulty saying it.	.675
e34	I appreciate just how their experiences feel to them.	.636
c24	I am able to be openly myself in our relationship, without hiding my vulnerabilities	.578

e2	I usually sense or realize how they are feeling	.565
c20	I am willing to say whatever is in my mind with them, including feelings that come up in me about either one of us, or how I see us getting along	.561
c12	I feel that I am genuinely myself with them	.544
c32	I know exactly what I feel in relation to them. I don't sense anything that's hard to face and admit to myself	.496
c8	I don't avoid or put off dealing with anything that matters between us.	.379
Unconditional acceptance (α C 0,78)		F2 V 17,02%
pr29	I feel friendly and warm towards them	.805
pr21	I care for them	.714
pr13	I appreciate and value them as people	.615
ua27	Whether they are expressing "good" thoughts and feelings, or "bad" ones, does not affect the way I feel towards them	.540
ua31	The way I feel about them doesn't depend on their feelings towards me	.529
pr5	I like them	.478
ua15	My liking or disliking of them isn't changed by anything they say about themselves	.461
pr1	I respect them as people	.448
ua39	I don't think that particular things they say or do alter the way I feel towards them	.406
ua7	Whether they are feeling happy or unhappy with themselves doesn't make me feel more or less positive towards them	.310

NOTE: E = EMPATHY; C = CONGRUENCE; UA = UNCONDITIONAL ACCEPTANCE; PR = POSITIVE REGARD;

TABLE 2 - CONSTRUCT VALIDATION OF HELPING RELATIONSHIP - POSITIVE ITEMS

HELPING RELATIONSHIP NEGATIVE ITEMS (n= 280)		T1
Avoidance mechanisms (α C 0,71)		F1 V 14,68%
c36	There are times when my outward response to them is quite different from the way I feel underneath	.652
c40	It bothers me when they try to ask or talk about certain things	.604
c16	I don't show my inner impressions and feelings with them	.544
e38	I respond to them rather automatically, not always taking in what they are experiencing	.517
ua35	Sometimes they seem to me a more worthwhile person than they do at other times	.498
c4	I tend to put on a role or front with them	.465
c28	Sometimes I am not at all comfortable with them, but we go on, outwardly ignoring it	.461
e14	At the time I don't realize how touchy or sensitive they are about some of the things we discuss	.459
e6	I hear their words but don't know how they feel inside	.390
ua3	The interest I feel in them depends on their words and actions	.365
ua23	If they get impatient or mad at me, I become angry or upset too	.317
Distance and impatience towards patients (α C 0,67)		F2 V 14,03%
pr25	I do feel disapproval of them	.728
pr33	I put up with them	.623
ua19	I would like them to be a particular kind of person	.601
pr17	I find them rather dull and uninteresting	.549

e30	I really don't understand them	.510
pr37	I do feel impatient with them	.379
e22	I screen out and don't pick up on some of their feelings	.357
pr9	I feel indifferent to them	.351
ua11	Depending on their actions, I have a better opinion of them sometimes than I do at other times	.346

NOTE: E = EMPATHY; C = CONGRUENCE; UA = UNCONDITIONAL ACCEPTANCE; PR = POSITIVE REGARD;

TABLE 3 - CONSTRUCT VALIDATION OF HELPING RELATIONSHIP - NEGSATIVE ITEMS

1.2.3 Convergent and divergent validation

The relationships between the factors of the helping relationship, burnout and well-being were investigated using Pearson product-moment correlation coefficient. Most correlations found were of medium strength. Strong correlations were found between avoidance mechanisms and emotional exhaustion and depersonalization.

1.2.4 Reliability

Cronbach alpha coefficients for the positive factors were .82 for factor 1, and .78 for factor 2. Cronbach alpha coefficients for the negative factors were .71 for factor 1, and .67 for factor 2.

The acceptable value for Cronbach alpha is .7. In order to establish test-retest reliability, Pearson bivariate correlations were performed on the 4 factors, with an interval of 4 months and results showed that that all four factors are reliable both internally and over time.

1.3 Validation and reliability of well-being questionnaire

1.3.1 Sensitivity

Sensitivity tests were performed to find items that were abnormally distributed, i.e. excessively skewed or kurtosed. This showed that most items fell within the acceptable range of -3.0 to + 3.0 for skewness, and -8.0 to + 8.0 for kurtosis. Item 41 showed inadequate sensitivity values and this should be taken into consideration with future use of the questionnaire. For a Likert scale of 1 to 6, an acceptable median would be within the range of 3 to 4. Results showed a slightly higher median for the factors of ‘close personal relationships and meaning in life’ and ‘self-confidence, dignity and meaning in face of adversity and illness’. Considering the nature of their work, which is a strong reminder of the need to cherish their loved ones and where they are in close contact daily with patients with a terminal condition with whom they are able to provide an atmosphere of dignity, these results were not considered to be a problem. For this reason, these items were maintained for factor analysis.

1.3.2 Construct validation

The 50 items of the scale, were subjected to principal components analysis (PCAn) and four factors were extracted. After examination of the individual items of each factor, it was decided to name each factor as follows:

Self-confidence, dignity and meaning in face of adversity and illness: in this context, this can be defined ‘as confidence in one’s ability to cope with aging and illness and to feel that life has meaning in spite of physical limitations’.

Close personal relationships and meaning in life: in this context, this can be defined as ‘cherishing personal relationships and striving to live life with meaning’.

Fear of dependence, physical degradation and loss of control: in this context, this can be defined ‘as fear of losing physical health, of physical pain, of being dependent on others and fear of not being able to be in control of one’s life’.

No time for family, friends and meaningful activities: in this context, this can be defined as ‘feeling that one is always in a hurry, with little time to pay attention to loved ones and to engage in activities that give meaning to their lives’

Alpha Cronbach (α C) test was performed on the final factors. The following table shows a summary of the results

SELF-CONFIDENCE, DIGNITY AND MEANING IN FACE OF ADVERSITY AND ILLNESS (α C 0,83)		F1 (V 18,61)
fp 49	I trust that when the time comes, I will receive what I need to deal with my physical pain	.613
fd 33	I feel the same person, even when I am not happy with my physical appearance	.606
fp 39	In spite of the physical pain that I may suffer from, life will continue to have meaning	.605
fp 29	I accept that physical pain, like any other, is part of life, whether it is my pain or other people's pain	.589
fp 19	I know that physical weaknesses will not stop me from continuing to contribute towards giving meaning to my life	.584
fu 12	I feel I have strategies and inner strength to deal with unforeseen situations that appear in my life	.572
fd 43	My body is not perfect, but I like it all the same	.526
fd 3	Apart from my physical aspect, I also value the emotional and	.497

	spiritual side of me	
fd 23	I can accept aging and the gradual degradation of my body as a natural stage in life	.489
fu 2	I face challenges with quite a lot of internal confidence	.480
fu 42	I feel that I have external resources to overcome the more complicated moments of my life	.478
fu 32	I accept difficult situations as part of my life journey and personal growth	.459
fp 9	Deep down, I know that I can tolerate more physical pain than I think	.421
fd 3	My dignity does not depend just on my usefulness in society	.384
ml 5	I feel fulfilled in my profession	.373
Close personal relationships and meaning in life (α C 0,67)		F2 (V11,25)
la 21	I make a point of finding time in my life to be with friends	.665
la 1	I have many real friends whom I can count on	.617
la 31	I normally phone friends and family, just to see how they are	.558
ml 25	I find ways to feel fulfilled in everyday life	.513
ml 15	Right now, I think that my life has meaning	.439
la 41	I normally tell people I love what they mean to me	.389

NOTE: LA = FEAR OF LONELINESS AND ABANDONEMENT; FU = FEAR OF THE UNKNOWN; FD = FEAR OF LOOSING DIGNITY AND BEING JUDGED; ML = FEAR PF NOT HVING MEANING IN LIFE; FP = FEAR OF PHYSICAL PAIN

TABLE 4 - CONSTRUCT VALIDATION OF POSITIVE ITEMS OF PESONAL WELL-BEING

FEAR OF DEPENDENCE, PHYSICAL DEGRADATION AND LOSS OF CONTROL (α C 0,84)		F1 V 18,08
fd 28	If I become ill, I would rather die than become dependant on others	.742

fp 24	The time of dying has no value. It is best to die quickly to end the suffering	.729
fd 18	If I cannot be an active and independent person, my life would lose all meaning	.701
fp 44	I cannot conceive living with a big physical disability	.657
fd 48	Physical degradation frightens me. It makes me feel reduced to nothing	.639
fp 14	Without physical health, it is not worth living	.613
fp 4	If I have to die, may it be quick	.609
fd 38	I am afraid of being a burden to others	.597
fp 34	I would rather die than be in physical pain	.562
fu 17	I am not at ease until have everything "under control"	.362
fu 47	I do everything I can to avoid any difficulties or instabilities in my life	.353
fu 27-	I feel the need to be informed of everything that surrounds me	.352
NO TIME FOR FAMILY, AND MEANINGFUL ACTIVITIES (α C 0,71)		F2 (V13,19)
la 46	I am always in a hurry and do not always notice or thank the caring gestures of other people	.679
ml 50	I do not regularly make a balance of my life, to avoid losing sight of what is important to me and gives meaning to my life	.645
la 26	I often do not show my appreciation to friends and family, and then regret it	.624
ml 20	There is no balance in my life between obligations and leisure	.513
la 36	I normally feel resentment towards others without trying to find a solution	.504
fd 8	I cannot feel that I am of value if I do not have a good physical appearance	.459

ml 30	I still need to identify what I still want to do in life before dying	.450
fu 7	I normally feel quite unconfident when faced with the unknown	.417
ml 10	I spend a lot of time doing activities I do not like	.412
la 6	If I were to die tomorrow, I would need to talk to some people close to me, to feel up to date with them	.389
fu 37	I do not feel capable of dealing with big changes in the "status quo" of my life	.314

NOTE: LA = FEAR OF LONELINESS AND ABANDONEMENT; FU = FEAR OF THE UNKNOWN; FD = FEAR OF LOOSING DIGNITY AND BEING JUDGED; ML = FEAR PF NOT HVING MEANING IN LIFE; FP = FEAR OF PHYSICAL PAIN

TABLE 5 - CONSTRUCT VALIDATION OF NEGATIVE ITEMS OF PERSONAL WELL-BEING

1.3.3 Convergent and divergent validation

The relationships between the factors of the well-being scale, helping relationship and burnout were investigated using Pearson product-moment correlation coefficient. The results showed mostly correlations of medium strength.

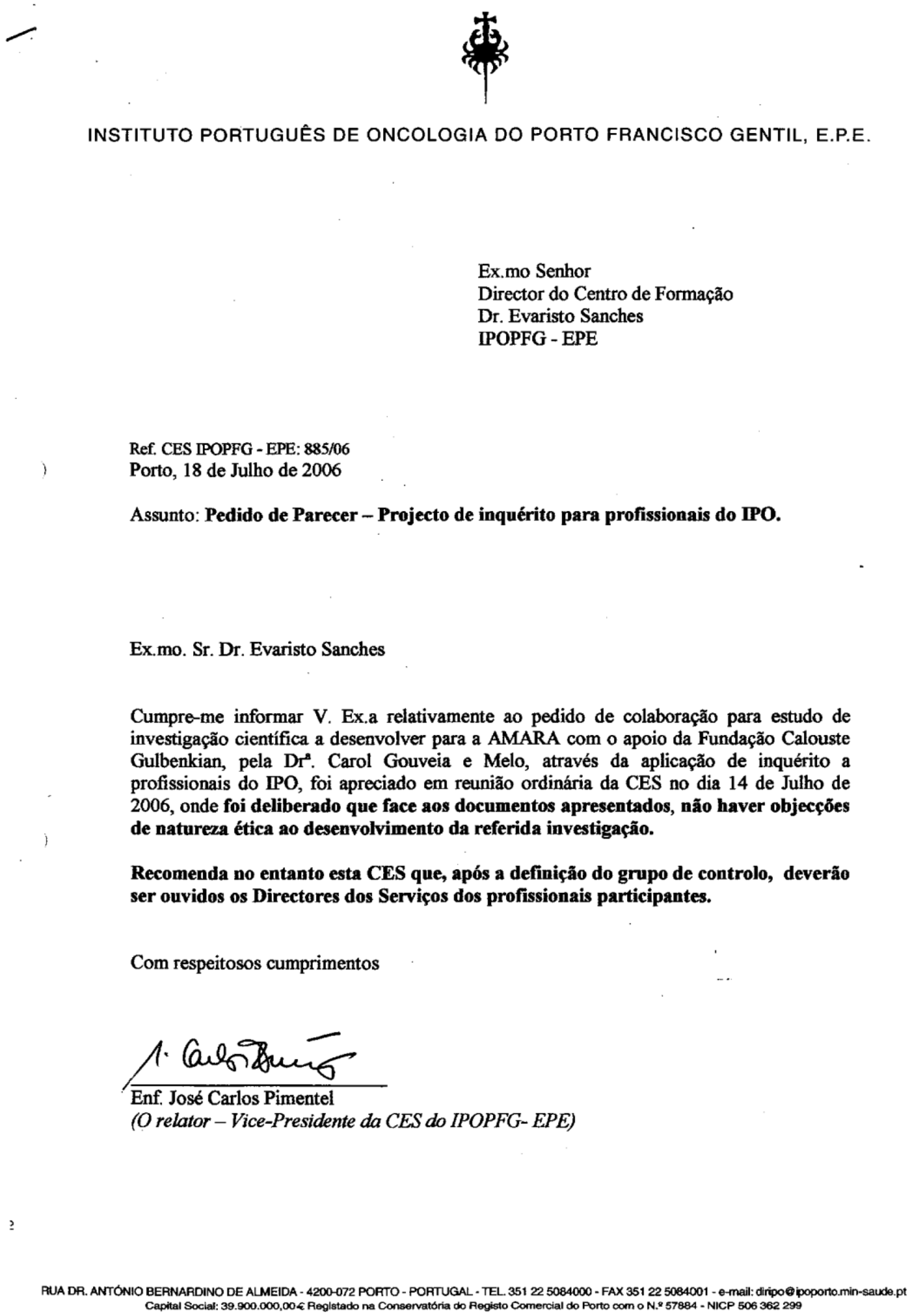
1.3.4 Reliability

Cronbach alpha coefficients for the positive factors were .83 for factor 1, and .67 for factor 2. Cronbach alpha coefficients for thenegative factors were .84 for factor 1, and .71 for factor 2. The acceptable value for Cronbach alpha is .7. In order to establish test-retest reliability, Pearson bivariate correlations were performed on the 3 factors, with an interval of 4 months and results showed that all four factors are reliable both internally and over time.

1.4 Death Anxiety

Although there was no questionnaire designed to measure death anxiety, it was possible to measure the issues related to death anxiety (existential fears) by joining the questionnaire of personal well-being, which was designed to measure existential well-being and existential fears, with one factor of the Barrett-Lennard Inventory: avoidance mechanisms. Avoidance mechanisms are the expression of death anxiety within the helping relationship. Therefore, the negative factors measuring death anxiety are: avoidance mechanisms, fear of dependence and physical degradation, and no time for family and meaningful activities. The positive factors, measuring absence of death anxiety are: self-confidence in the face of adversity and illness, close personal relationships, and meaning in life. Factors related to personal relationships and meaning in life were included because, as mentioned earlier, these existential factors can increase anxiety in patients with a terminal condition if neglected earlier in life and they are also important issues affecting healthy people — and, subsequently, HCWs.

APPENDIX 16 – ETHICAL CONSENT FROM IPO HOSPITAL TO SEND QUESTIONNAIRES TO A CONTROL GROUP



INSTITUTO PORTUGUÊS DE ONCOLOGIA DO PORTO FRANCISCO GENTIL, E.P.E.

Ex.mo Senhor
Director do Centro de Formação
Dr. Evaristo Sanches
IPOPFG - EPE

Ref. CES IPOPFG - EPE: 885/06
Porto, 18 de Julho de 2006

Assunto: **Pedido de Parecer – Projecto de inquérito para profissionais do IPO.**

Ex.mo. Sr. Dr. Evaristo Sanches

Cumpre-me informar V. Ex.a relativamente ao pedido de colaboração para estudo de investigação científica a desenvolver para a AMARA com o apoio da Fundação Calouste Gulbenkian, pela Drª. Carol Gouveia e Melo, através da aplicação de inquérito a profissionais do IPO, foi apreciado em reunião ordinária da CES no dia 14 de Julho de 2006, onde **foi deliberado que face aos documentos apresentados, não haver objecções de natureza ética ao desenvolvimento da referida investigação.**

Recomenda no entanto esta CES que, após a definição do grupo de controlo, deverão ser ouvidos os Directores dos Serviços dos profissionais participantes.

Com respeitosos cumprimentos

Enf. José Carlos Pimentel
(O relator – Vice-Presidente da CES do IPOPFG- EPE)

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APPENDICES 17 to 26 – TRANSCRIPTS OF QUALITATIVE DATA

APPENDIX 26 – LETTER OF INVITATION TO PARTICIPATE IN THE RESEARCH

Dear Clinical Director

Under the bid for funding of projects in the area of palliative care, the Calouste Gulbenkian Foundation approved the research project "Quality education in the area of palliative care", presented by AMARA – Association for Dignity in Life and Death, which will be coordinated by Carol Gouveia Melo. This grant enables us to bring to your institution, a training intervention for your teams working with the terminally ill, for €60 per person, with the remainder paid by the Calouste Gulbenkian Foundation.

The aim of this research is to evaluate and demonstrate the importance of having appropriate training for those working with the terminally ill. It proposes to undertake a 6 day intervention on the psycho-existential issues related to death and dying and helping relationship skills with health care workers who work with terminally ill patients and compare the levels of burnout, well-being and helping relationship attitudes before and after the intervention, in order to demonstrate the importance of addressing burnout and the consequent improvement of care provided to patients.

The intervention is based on a course conceived by Helena-Hermine Aitken, vice-President of AMARA, and described below:

Title: "Life and Death: the same preparation".

ACQUIRED KNOWLEDGE

- Understanding of existential issues that affect patients with a terminal condition, and their families;
- Understanding of our own resolved and unresolved existential issues;
- Understanding of the influence of one's own individuality (personality and temperament traits, etc.) on the relationship with patient;
- Understanding the meaning of our role as professionals who care for patients with a terminal condition and their families;
- Relaxation and meditation techniques to manage stress;
- Understanding of grief and bereavement in patients with a terminal condition and their family;
- Understanding of patients' spiritual needs;
- Basic understanding of Person Centred Therapy.

ACQUIRED SKILLS

- Capacity to empathize with the patient and family in a close and meaningful relationship and simultaneously maintain one's own internal congruence;
- Capacity to be aware of one's own existential issues and those of the patient, as well as the effect these can have on one's own feelings;
- Capacity to detect symptoms of burnout in any of its dimensions in ourselves and seek help when needed;

- Capacity to maintain physical and emotional presence with a patient suffering from physical pain and degradation;
- Capacity to perform relaxation techniques on self to manage stress;
- Capacity to make meaningful questions regarding the care we provide;
- Capacity to work in a team, giving and receiving to and from it;
- Capacity to provide emotional and spiritual care for the patient and family.

METHODOLOGY

- Sharing within group therapy;
- Practical exercises that promote reflection and self-awareness;
- Creating a team vision;
- Relaxation sessions;
- Role-playing;
- Psychodrama;
- Exercises of active listening.

THEMES APPROACHED

Self-Reflection / Self-Awareness

Physical: my own Body

- Self-care: what am I doing to keep myself physically healthy? (diet, exercise, relaxation);
- Natural aging: accepting signs of aging, loss of beauty;
- Dealing with the prospect of losing independence and mobility. Accepting dependency on others;
- Dealing with the prospect of living with: physical degradation, deformity and pain;
- Acknowledge ones own feelings when caring for patients suffering from physical degradation, deformity and pain;
- Dealing with the acceptance of one’s own dead body: how do I imagine my body after death; how would I like my body be treated after death;

Existential Issues: Emotional and Spiritual

- State of relationships with loved ones: meaningful relationships, communication and expressing feelings with loved ones; time dedicated to family and friends; issues of forgiveness and gratitude; how would I like to be remembered after my death, and what am I doing to contribute towards this?
- My role in my family: being a child, a parent, a relative and my different reactions in the presence of my loved one’s suffering;
- Capacity of being alone: how do I deal with emotional/physical suffering when alone? Do I feel helplessness or have resilient strengths? Being alone while suffering is a different concept than loneliness (which can also be experienced when someone is present);

- Living life with meaning: do my present activities contribute towards a sense of fulfilment and meaning? Am I wasting a lot of time on activities that are meaningless to me? What are my goals in life? What is really important to me? If I knew I were to die shortly and looked back on my life, would I have a sense of having lived well? If not, what can I change?
- Issues of uncertainty and lack of control in life: not everything is under our control in life. How do I deal with uncertainty? What are my personal resources and coping mechanisms to deal with difficult situations in life? An analysis of past life obstacles (any loss, difficulty in life, or traumatic experience) and how we dealt with them will help us get to know our personal strengths and knowing our resources may reduce fear of the unknown;
- Personal bereavement issues: am I in bereavement? When someone I loved died, what were my needs, or what do I think my needs would be if someone died? What would I need around me for this to happen?
- My own death: if I were dying, what would I like to be feeling? What would I need around me for this to happen?
- Dignity: what are my cornerstones of dignity? When is my body in dignity, when am I in dignity? How can I facilitate dignity tutelage and preservation in patients and caregivers?
- My own religious and spiritual beliefs and needs: understanding the difference between beliefs and certainties; my religion and my spirituality; how do I nurture my spiritual self? Ensuring that our spiritual beliefs and needs are not imposed on our patients;
- Motivational issues: why did I choose to work in palliative care? If it just happened (and I did not choose): where does my work motivation stem from? Work motivation in palliative care as a process.

<u>Helping Relationship:</u>

- Five stages of grief – Elizabeth Kübler-Ross;
- Bereavement in adults and children;
- Spiritual needs of patients with a terminal condition;
- Active listening and how to develop a quality of presence within the relationship.

The target population of the research will consist preferably of the whole team of the unit who care for terminally ill patients, from doctors, nurses to nursing aides. This condition is important for the whole team to have a consistent approach with the same goals, which will facilitate group collaboration and help reduce burnout and improve their helping relationship skills.

The hypotheses of the research are the following:

- The intervention is an effective instrument to improve levels of HCWs' personal well-being and perception of their competencies in helping relationship skills.
- As a result of an improvement in personal well-being and perception of their own competencies of helping relationship skills, there would be an expected reduction in levels of burnout.

- As a result of an improvement in personal well-being, there would be an expected improvement in the HCWs' perception of the quality of their helping relationship with the patient.

We intend to request that the questionnaires be filled in one week before the beginning of the intervention and 4 months after the intervention, to understand if there is any significant change.

The following questionnaires will be used:

- *Burnout*, specially designed for health care workers who care for patints with a terminal condition.
- Well-being, which will be designed to evaluate fears and anxieties in relastion to life and death, and how these affect daily life.
- Barrett-Lennard Relationship Inventory (positive retgard, empathy, congruence and unconditional acceptance).

We are at your disposal for any additional information you may need regarding the content / calender of the inteventions (e-mail: carol.costeloe@amara-project.org) and look forward to hearing from you.

Yours sincerely

Carol Costeloe de Gouveia e Melo
Formação
AMARA-Associação pela Dignidade na Vida e na Morte
Carol.costeloe@amara-project.org
Tlm: 91 616 2911

APPENDIX 27 – LETTER OF CONSENT FROM PARTICIPANTS

This intervention has been funded by the Calouste Gulbenkian Foundation and is part of a research project designed to understand the importance of psycho-existential personal development and helping relationship training in end of life care to reduce levels of burnout and improve helping relationship skills.

It is therefore a requirement for participating in the course, to fill in the questionnaires described in the letter of presentation, before the intervention and four months after.

I ____, delare that I accept these conditions to participate in the course "Life and Death, the same preparation".

Date:_____/______/______

APPENDIX 28 – EXAMPLE OF QUALITATIVE INTERVIEW, THEMATIC CATEGORY STRUCTURE AND CONTENT ANALYSIS

Interview with a nurse from palliative care unit

Before I turned on the tape, I would just chat for a bit, ask permission again to record, explain anonymity, and then I started recording. This interview has been translated from Portuguese.

Carol: – **A few months ago, you did the AMARA training course. I would like to know what impact the course had on you. What changes occurred, positive or negative, after the course in terms of your personal and professional life and in your relationship with your colleagues, patients and families?**

Nurse: -For me, the course helped me a lot, first by finding resources I thought I didn't have, or thought that I wasn't able to cope with things, and this helped me a lot, personally and professionally. Professionally, it helped me be more tolerant with people, with my colleagues and with families, because there are times that I feel and felt, I thought I wasn't dealing well with the situation, or that I didn't have any more patience to face daily work and this helped me to understand and accept better people's suffering, and in terms...mainly with the team.... it helped me to face better my relationship with my colleagues and to try and understand why they had certain attitudes that people sometimes have. This was important for me.

- It seems to have helped you a lot with team work. Would you like to tell me more about that?

- Before, I had a lot of difficulty in telling people when I thought they were doing something wrong, or proceeding badly or well.

- Do you mean that after the course you felt that you became more assertive? More sure of yourself?

- Yes, before I used non verbal expressions to show what I felt and now I use verbal expressions more. I say what I think directly.

- How does this affect the atmosphere at work, or your relationships?

- It is better for me, and I think that for my colleagues too, although, to be sincere, I feel that we are now back to where we were before the course. The atmosphere is very bad again.

- Things were better after the course, but now they are worse again.

- Perhaps if we had these sessions more frequently and with more people coming.

- How long did the good atmosphere last?

- Two to three months. What I feel now is that everyone is irritated, very nervous, and that they protest about anything and answer back. Then one answers badly and the others....it's like a snowball, everyone starts to answer badly and the bad atmosphere starts again. I think that people are saturated. We come to work, do our best and I feel that we need to be told that today, in spite of all the confusion from overwork, you were tireless, you did your best, and we never hear this and I think that positive reinforcements are also important and at the moment, what we hear most are negative reinforcements. This is the worst (that can happen) - we get discouraged, and we come to work because we have to work. I speak for myself, I come to work because it is what I like doing, it is with the patients that I like being with, but if you asked me if there were any teams members I would want to be with? No. At the moment, no.

-In your opinion, what could be done to improve this?

- I don't know. What I think is that there are many people here who are thinking of going elsewhere, and they are here because they haven't yet managed to go somewhere else. They are a bit forced. Or else, some want to be here, but are unable to revert this situation of the bad atmosphere becoming better. I don't know. Perhaps for some people monthly meetings might help because they could talk about what they felt during this time, what they are feeling, the anger they feel, because what we notice is that people are really angry, and then there is something I think is really bad, which is making decisions that affect the team and affect the unit, for worse or for worse and not telling anyone. We find out because one person says this and another says that and I think this is bad for the atmosphere.

- This bad atmosphere, does it affect your work?

- I think so, because it is like this: when you don't feel good, your work is not the same. We are also not well and we can't show that we are. Something fails, we can try to disguise it for a while and for a while we manage but then we don't.

- What changes have you noticed, if any, before and after the course? At a personal level that may have reflected on your work, or in your relationship with the patients or family, or in coping with suffering, or within the team?

-Where I felt most changes was in teamwork, but personally, I see this as an advantage and a disadvantage. Then I also felt a closer relationship with the team members with whom I did the course, because I got to know them in a different way than I was used to, and this motivates me to try to know the other team members, the other people, like (in the same way as) I knew the people who did the course with me.

- You felt like getting to know the others better as well.

-We are limited to the people who did the course with us, which is good, but we created a friendship that would also be good to create with the others.

-It made things easier work wise with your colleagues, is that what you are saying?

-Yes. With patients as well, but there were aspects of the training that I already knew. Theoretical aspects, but of course, it is perfecting what we know and putting into practise what we know. And in this sense, I think it is helpful.

- Could you explain what you mean by helpful?

-Because sometimes, the fact that we have someone who makes us feel "what if we were to die in a year, what would you want to do", and say this to other people. I think we have thought about this on our own, but to say it out loud to others is strong.

-You mean you became more aware, conscious? And this helped putting things into practise? The fact that it wasn't just theoretical thinking, but to have put things into words verbally helped the next step to be putting things into action?

-Yes, yes. In this way we trained our capacity to empathize with the patient and try to see, perceive what the person is thinking and why he is suffering.

- You mean you became more alert?

- Of course, exactly. Because sometimes we know the patient is suffering, but then we have to discriminate which part. If it is the physical part, psychological part, in order to help them in their suffering, because we are there trying to help them in their suffering, but this is very vague, we have to get the cake and break it into slices and decode each bit to obtain results.

- This is where you think the course helped?

- I think so.

- Is there anything else you would like to add?

- Perhaps we have as tendency to judge others straight away and after a certain phase (period) of working we facilitate this (meaning they start to judge more easily without giving it a second thought) and I think it alerted me not to judge....it is because the patient is suffering that he expresses himself in a certain way and I make inadequate judgements. We should think twice, right? I think that in this, it helped. (the portuguese was a bit confusing, and I left the original in): *Se calhar nós temos sempre a tendência para julgar os outros à partida e depois de uma certa fase em que estamos a trabalhar facilitamos muito e acho que me alertou para não estar a julgar pela tal questão o doente está a sofrer mas está a sofrer por isso mesmo expressa de alguma maneira e eu faço um juízo de valores completamente desadequado. Convém pensar duas vezes não é? Eu acho que nisso ajudou.*

- You are more empathic and this helps you to accept the other person without feeling resentment?

- And anger too, or thinking that it is something directed at me, or because the person is the way he is, but it is not because he is the way he is, but there is a reason for it.

- You don't take things so personally

-Exactly.

- **It has been some months. Has anything stayed or do you think that with time things fade? Or that over time there should be more small group meetings?**

- In my opinion, that is essential

- You feel that some things have got lost over the months?

- Some things get lost. We need to see and remember things - that we often know already - but out loud. It is a commitment we make with others, a commitment in the good sense. I think that is needed.

- How do you think more meetings could be helpful?

- For sure they would be of utmost importance, because units change, even ours...we changed our methods, we changed many things, which is normal .... units change and it is good to change, we don't stagnate and change is good and as things change we need to remember again this and that, we work like this and we need to be like that and up to now it has been good, but now we need to have that behaviour...

- I see, once in a while you need an overview of the situation to organise yourselves?

-Organize ourselves in every way and in all the changes that occur at work, which are inevitable in every way and then we also have times when the type of patients change and maybe there are times more prone to fragilities and we may need more sessions. I am afraid that some things may get lost.

- Is there anything you would like to add about the course? Anything you were not happy with, any suggestions?

- Only what I wrote in the questionnaire, to use audiovisual media.

THEMATIC CATEGORY STRUCTURE FROM NVIVO

Node Structure
Interviews + written questions

Name

Node **(154)**

Nodes\\Tree Nodes

positive changes

- personal changes
    - self awareness- know myself better
    - self esteem
    - internal congruence
        - innter peace
        - able to say what I feel
        - accept my way of being
        - true to my values
        - DS\
        - self observation
        - emotional and intellectual stability
        - know what I want
    - well being in daily life
        - work less to enjoy life more
        - more appreciation for life and people
        - let go of unimportant matters
        - live with meaning in life
        - not much change
    - confidence and assertiveness

- personal resources
- respect my limits
- better personal relationships
- self care
- cope better with loss and suffering
- accept my vulnerabilities

work environment

- better relationship with colleagues
  - more tolerance and less judgemental
  - change to positive opinion
  - more sharing and appreciation
  - stronger group cohesion and team work
  - better understanding of colleagues
  - better communication
  - resolution of conflict
  - more avaliability and time to listen to them
  - more trust
- relationship with patient
  - Serenity
    - accept that cannot control everything
  - more patience
  - more attentive and able to care for patient's needs
  - more sharing
  - more faith in patient's resources to cope
  - more capable to give emotional and spiritual support
  - empathy and listening skills
  - unconditional acceptance and positive regard
  - better communication
  - able to avoid conspiracy of silence
  - Compassion

    - congruent-no defences
    - more affectionate with patient
    - how to be present and respectful
  - relationship with family
    - tolerant and less judgemental
    - better communication in family meetings
    - create more time to listen to them
    - more open with the family
    - better understanding and capacity to help
      - more attentive to non verbal communication
    - more genuine
  - reduction in death anxiety
    - ability to work with dying children or young people
  - more professional fulfillment
  - less burnout
  - improvement in knowledge and capacity to help
  - more organised and efficient
  - clarification of position towards euthanasia
  - more motivated

Needs

- receive motivation
- better communication with superiors
- more education of this type for doctors
- individual sessions
- more quality time to be with patient
- more training
  - group encounters
    - accepting commitment to change
  - training in communication with collegues
  - training in communication with patient and family
  - training in emotional relationship with body of patient and physical degradation

spiritual accompaniment

meaning in life

negative aspects still present at work after intervention

conflicts at work

emotional exhaustion

decreased efficiency

low self esteem and self confidence

work overload

Depersonalization

difficulty in communication

difficulty in showing my feelings

feeling helpless

therapeutic attributes and effects of training intervention

sharing in a group

practical exercises

therapeutic atmosphere

liberty to share feelings

I am not alone in my fears and difficulties

able to hear feedback from colleagues

structure+content of the course and teaching method

attitude of trainers

non directive

general feedback on course

what I learnt from intervention

value of spirituality

Dignity in life and death-circle of life

how to care in the terminal phase

stop and think

Difficulties present before the intervention

Intimacy

dealing with suffering

dealing with silences

emotional exhaustion

avoidance mechanisms

work overload

receiving from others

controling my emotions - congruence

no time for patient - depersonalization

patient died before I said goodbye

not being understood at home

being seen as cold

Boundaries

complicated and - or manipulative famililies

image people have palliative care - death shelf

Conflicts

separation and or death anxiety

guilt when patient does not get better

infantilizing patient

seeing palliative treatment as giving up

disgust and symbolic contamination

unconditional acceptance of difficult patient

giving bad news by phone

what to say-conspiracy of silence

really empathysing

communication with cognitively impaired

time management

share difficulties and weaknesses with colleagues

isolation and responsibility of being in charge

feeling helpless

no group supervision

not feeling appreciated by superiores

Suggestions for the intervention

- less hours per day
- other methods of presentation
- less exposure of self
- more case studies
- no changes needed

negative aspects of intervention

- felt judged by one trainer
- unable to trust group
- learnt nothing
- broken confidentiality
- creates separate groups

EXAMPLE OF CONTENT ANALYSIS RESULTS USING NVIVO

01-02-2014 11:22

Coding Summary By Node

Interview with nurse from palliative care unit

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Node

Nodes\\Tree Nodes\\needs\better communication with superiors

Document

Internals\\interview with pc nurse

No 0,0164 1

1 CM 01-02-2014 9:13

there is something I think is really bad, which is making decisions that affect the team and affect the unit, for worse or for worse and not telling anyone.

Nodes\\Tree Nodes\\needs\more training\group encounters

Document

Internals\\interview with pc nurse

No 0,0616 3

1 CM 01-02-2014 9:05

Perhaps if we had these sessions more frequently and with more people coming

2 CM 01-02-2014 9:11

Perhaps for some people monthly meetings might help because they could talk about what they felt during this time, what they are feeling, the anger they feel, because what we notice is that people are really angry,

3 CM 01-02-2014 11:04

Organize ourselves in every way and in all the changes that occur at work, which are inevitable in every way and then we also have times when the type of patients change and maybe there are times more prone to fragilities and we may need more sessions. I am afraid that some things may get lost

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Tree Nodes\\needs\more training\group encounters\accepting commitment to change

Document

Internals\\interview with pc nurse

No 0,0208 1

1 CM 01-02-2014 11:03

Some things get lost. We need to see and remember things - that we often know already - but out loud. It is a commitment we make with others, a commitment in the good sense. I think that is needed.

Nodes\\Tree Nodes\\needs\receive motivation

Document

Internals\\interview with pc nurse

No 0,0431 1

1 CM 01-02-2014 9:08

We come to work, do our best and I feel that we need to be told that today, in spite of all the confusion from overwork, you were tireless, you did your best, and we never hear this and I think that positive reinforcements are also important and at the moment, what we hear most are negative reinforcements. This is the worst (that can happen) - we get discouraged, and we come to work because we have to work.

Nodes\\Tree Nodes\\negative aspects still present at work\conflicts at work

Document

Internals\\interview with pc nurse

No 0,0681 3

1 CM 01-02-2014 9:02

It is better for me, and I think that for my colleagues too, although, to be sincere, I feel that we are now back to where we were before the course. The atmosphere is very bad again.

2 CM 01-02-2014 9:05

What I feel now is that everyone is irritated, very nervous, and that they protest about anything and answer back. Then one answers badly and the others....it's like a snowball, everyone starts to answer badly and the bad atmosphere starts again.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

3 CM 01-02-2014 9:09

I speak for myself, I come to work because it is what I like doing, it is with the patients that I like being with, but if you asked me if there were any teams members I would want to be with? No. At the moment, no.

Nodes\\Tree Nodes\\negative aspects still present at work\emotional exhaustion

Document

Internals\\interview with pc nurse

No 0,0036 1

1 CM 01-02-2014 9:07

I think that people are saturated.

Nodes\\Tree Nodes\\negative aspects still present at work\work overload

Document

Internals\\interview with pc nurse

No 0,0431 1

1 CM 01-02-2014 9:08

We come to work, do our best and I feel that we need to be told that today, in spite of all the confusion from overwork, you were tireless, you did your best, and we never hear this and I think that positive reinforcements are also important and at the moment, what we hear most are negative reinforcements. This is the worst (that can happen) - we get discouraged, and we

Nodes\\Tree Nodes\\positive changes\personal changes\confidence and assertiveness

Document

Internals\\interview with pc nurse

No 0,0271 2

1 CM 01-02-2014 9:01

Before, I had a lot of difficulty in telling people when I thought they were doing something wrong, or proceeding badly or well.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On
				2	CM	01-02-2014 9:01

Yes, before I used non verbal expressions to show what I felt and now I use verbal expressions more. I say what I think directly.

Nodes\\Tree Nodes\\positive changes\personal changes\personal resources

Document

Internals\\interview with pc nurse

No		0,0205	1			
				1	CM	01-02-2014 8:50

For me, the course helped me a lot, first by finding resources I thought I didn't have, or thought that I wasn't able to cope with things, and this helped me a lot, personally and professionally.

Nodes\\Tree Nodes\\positive changes\work environment\better relationship with colleagues\better understanding of colleagues

Document

Internals\\interview with pc nurse

No		0,0208	1			
				1	CM	01-02-2014 9:00

mainly with the team.... it helped me to face better my relationship with my colleagues and to try and understand why they had certain attitudes that people sometimes have. This was important for me

Nodes\\Tree Nodes\\positive changes\work environment\better relationship with colleagues\more tolerance and less judgemental

Document

Internals\\interview with pc nurse

No		0,0101	1			
				1	CM	01-02-2014 8:53

Professionally, it helped me be more tolerant with people, with my colleagues and with families,

Nodes\\Tree Nodes\\positive changes\work environment\better relationship with colleagues\stronger group cohesion and team work

Document

Internals\\interview with pc nurse

No 0,0044 1

1 CM 01-02-2014 9:20

Where I felt most changes was in teamwork,

Nodes\\Tree Nodes\\positive changes\work environment\improvement in knowledge and capacity to help

Document

Internals\\interview with pc nurse

No 0,0243 1

1 CM 01-02-2014 10:54

With patients as well, but there were aspects of the training that I already knew. Theoretical aspects, but of course, it is perfecting what we know and putting into practise what we know. And in this sense, I think it is helpful.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Tree Nodes\\positive changes\work environment\reduction in death anxiety

Document

Internals\\interview with pc nurse

No 0,0070 1

1 CM 01-02-2014 8:58

this helped me to understand and accept better people’s suffering,

Nodes\\Tree Nodes\\positive changes\work environment\relationship with family\tolerant and less judgemental

Document

Internals\\interview with pc nurse

No 0,0543 2

1 CM 01-02-2014 8:53

Professionally, it helped me be more tolerant with people, with my colleagues and with families,

2 CM 01-02-2014 11:00

Perhaps we have as tendency to judge others straight away and after a certain phase (period) of working we facilitate this (meaning they start to judge more easily without giving it a second thought) and I think it alerted me not to judge....it is because the patient is suffering that he expresses himself in a certain way and I make inadequate judgements. We should think

Nodes\\Tree Nodes\\positive changes\work environment\relationship with patient\empathy and listening skills

Document

Internals\\interview with pc nurse

No 0,0225 2

1 CM 01-02-2014 8:56

this helped me to understand and accept better people's suffering,

Reports\\Coding Summary By Node Report Page 6 of 11

01-02-2014 11:22

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

2 CM 01-02-2014 10:57

In this way we trained our capacity to empathize with the patient and try to see, perceive what the person is thinking and why he is suffering.

Nodes\\Tree Nodes\\positive changes\work environment\relationship with patient\more attentive and able to care for patient's needs

Document

Internals\\interview with pc nurse

No 0,0401 1

1 CM 01-02-2014 10:59

Of course, exactly. Because sometimes we know the patient is suffering, but then we have to discriminate which part. If it is the physical part, psychological part, in order to help them in their suffering, because we are there trying to help them in their suffering, but this is very vague, we have to get the cake and break it into slices and decode each bit to obtain results.

Nodes\\Tree Nodes\\positive changes\work environment\relationship with patient\more capable to give emotional and spiritual support

Document

Internals\\interview with pc nurse

No 0,0401 1

1 CM 01-02-2014 10:59

Of course, exactly. Because sometimes we know the patient is suffering, but then we have to discriminate which part. If it is the physical part, psychological part, in order to help them in their suffering, because we are there trying to help them in their suffering, but this is very vague, we have to get the cake and break it into slices and decode each bit to obtain results.

Reports\\Coding Summary By Node Report Page 7 of 11

01-02-2014 11:22

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Tree Nodes\\positive changes\work environment\relationship with patient\unconditional acceptance and positive regard

Document

Internals\\interview with pc nurse

No 0,0629 2

1 CM 01-02-2014 11:00

Perhaps we have as tendency to judge others straight away and after a certain phase (period) of working we facilitate this (meaning they start to judge more easily without giving it a second thought) and I think it alerted me not to judge....it is because the patient is suffering that he expresses himself in a certain way and I make inadequate judgements. We should think

2 CM 01-02-2014 11:01

And anger too, or thinking that it is something directed at me, or because the person is the way he is, but it is not because he is the way he is, but there is a reason for it.

Nodes\\Tree Nodes\\therapeutic attributes and effects of training course\negative aspects\creates separate groups

Document

Internals\\interview with pc nurse

No 0,0595 2

1 CM 01-02-2014 9:28

Where I felt most changes was in teamwork, but personally, I see this as an advantage and a disadvantage. Then I also felt a closer relationship with the team members with whom I did the course, because I got to know them in a different way than I was used to, and this motivates me to try to know the other team members, the other people, like (in the same way as) I knew

2 CM 01-02-2014 9:29

We are limited to the people who did the course with us, which is good, but we created a friendship that would also be good to create with the others.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Nodes\\Tree Nodes\\therapeutic attributes and effects of training course\negative aspects\learnt nothing

Document

Internals\\interview with pc nurse

No		0,0056	1			
				1	CM	01-02-2014 10:52

there were aspects of the training that I already knew

Nodes\\Tree Nodes\\therapeutic attributes and effects of training course\suggestions\other methods of presentation

Document

Internals\\interview with pc nurse

No		0,0027	1			
				1	CM	01-02-2014 11:05

to use audiovisual media.

Nodes\\Tree Nodes\\therapeutic attributes and effects of training course\therapeutic attributes and effects of training course\sharing in a group

Document

Internals\\interview with pc nurse

No 0,0262 1

1 CM 01-02-2014 10:56

Because sometimes, the fact that we have someone who makes us feel “what if we were to die in a year, what would you want to do”, and say this to other people. I think we have thought about this on our own, but to say it out loud to others is strong

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Relationship

Relationships\\better communication with superiors (impacts on) receive motivation

Document

Internals\\interview with pc nurse

No 0,0276 1

1 CM 01-02-2014 9:16

there is something I think is really bad, which is making decisions that affect the team and affect the unit, for worse or for worse and not telling anyone. We find out because one person says this and another says that and I think this is bad for the

Relationships\\conflicts at work (contributes towards) decreased efficiency

Document

Internals\\interview with pc nurse

No 0,0216 1

1 CM 01-02-2014 9:18

when you don't feel good, your work is not the same. We are also not well and we can't show that we are. Something fails, we can try to disguise it for a while and for a while we manage but then we don't.

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On

Relationships\\conflicts at work (impacts on) relationship with patient

Document

Internals\\interview with pc nurse

Aggregate	Classification	Coverage	Number Of Coding References	Reference Number	Coded By Initials	Modified On
No		0,0216	1			
				1	CM	01-02-2014 9:18

when you don't feel good, your work is not the same. We are also not well and we can't show that we are. Something fails, we can try to disguise it for a while and for a while we manage but then we don't.

APPENDIX 29 – ETHICAL CONSENT FROM THE UNIVERSITY OF KENT

University of Kent
Centre for Professional Practice

Psychotherapy & Mental Health

DR SUZANNE MARTIN
DIRECTOR OF GRADUATE STUDIES (RESEARCH)
Dialling Code for Canterbury:
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Mrs Carol Gouveia E Melo
Rua Gil Vicente 12
Bloco C R/c
2775-198 Parede
Portugal

11 April 2014

Dear Carol
Carol Maria Olga Costeloe Gouveia E Melo PhD in Medicine and Health Sciences

We have checked the records of the Research and Ethics Committee at the Centre for Professional Practice at the University of Kent and we are unable to find written confirmation of the approval of this student's application for ethical approval. However since 2008 the Centre has undergone major changes, with two moves, three Heads of Centre and several Chairs of the Research and Ethics Committee and the records in the archive are incomplete.

However on questioning members of the group who were actively involved in the Committee at this time there is a consensus of opinion that this student had submitted her proposal and this was granted ethical approval.

I am therefore happy to confirm that this project did receive ethical approval for the University of Kent.

Yours sincerely,

Suzanne Martin

Dr Suzanne Martin
Director of Graduate Studies (Research)

APPENDIX 30 – ARTICLES PUBLISHED

- Gouveia e Melo, C. & Oliver, D., 2012. Assessing burnout in portuguese health care workers who care for the dying:validity and reliability of a burnout scale using exploratory factor analysis. *Psychology, Community & Health,* Volume 1(3), pp. 257-272.

- Gouveia e Melo, C. & Oliver, D 2011. Can emotional support for health care workers to cope with death anxiety reduce burnout and improve patient care? *Journal of Palliative Care*, 24:4 Winder

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(Authors and entities cited in the bibliography are in italics)